University of Alberta

Wiring Northern Networks: Ethics in Participatory Research with Aboriginal Communities Using the Internet

by

Micaela Brown

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the

requirements for the degree of *Master of Science in Family Ecology and Practice*

Department of *Human Ecology*

Edmonton, Alberta
Fall 2005

0-494-09132-0

Library and Archives Canada

Published Heritage Branch

395 Wellington Street
Ottawa ON K1A 0N4
Canada

Bibliothèque et Archives Canada

Direction du Patrimoine de l'édition

395, rue Wellington
Ottawa ON K1A 0N4
Canada

Your file *Votre référence*
ISBN:
Our file *Notre reference*
ISBN:

NOTICE:
The author has granted a non-exclusive license allowing Library and Archives Canada to reproduce, publish, archive, preserve, conserve, communicate to the public by telecommunication or on the Internet, loan, distribute and sell theses worldwide, for commercial or non-commercial purposes, in microform, paper, electronic and/or any other formats.

The author retains copyright ownership and moral rights in this thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without the author's permission.

AVIS:
L'auteur a accordé une licence non exclusive permettant à la Bibliothèque et Archives Canada de reproduire, publier, archiver, sauvegarder, conserver, transmettre au public par télécommunication ou par l'Internet, prêter, distribuer et vendre des thèses partout dans le monde, à des fins commerciales ou autres, sur support microforme, papier, électronique et/ou autres formats.

L'auteur conserve la propriété du droit d'auteur et des droits moraux qui protège cette thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

In compliance with the Canadian Privacy Act some supporting forms may have been removed from this thesis.

While these forms may be included in the document page count, their removal does not represent any loss of content from the thesis.

Conformément à la loi canadienne sur la protection de la vie privée, quelques formulaires secondaires ont été enlevés de cette thèse.

Bien que ces formulaires aient inclus dans la pagination, il n'y aura aucun contenu manquant.

Canada

ABSTRACT

The following study is a qualitative, exploratory investigation attempting to identify the salient ethical issues regarding the use of the Internet as a health research and dissemination tool in northern Aboriginal communities, as they are perceived by community members, technical service providers, and outside researchers associated with Network North, a collaborative and community-based northern research initiative. Data from documents, semi-structured interviews, and observations were collected and comparatively analyzed, aiming to illuminate common ethical principles and areas of potential ethical conflict between participants at the community, technical service, and research levels. Major findings indicate important commonalities and differences both within and between participants at each of these levels, pointing to the need for a thorough understanding of northern community structures and dynamics, increased scrutiny regarding the roles and responsibilities of technical service providers; and careful ethical judgment on the part of researchers.

ACKNOWLEDGEMENTS

This research would not have been possible without the help of many different people and organizations. I sincerely apologize to those I am about to forget … For outstanding guidance and support (academically and otherwise), Dr. Nancy Gibson. For making this project possible, all of my interview participants. For a gracious welcome, incredible hospitality, and an amazing experience (both for my research and my life), Rita Mueller, Jerry and Chris Baron, Jim Martin, Colleen Davison, Michael Bottermans, the Dogrib Community Services Board, all the staff and students at Chief Jimmy Bruneau Regional School, and the entire community of Rae-Edzo. For unquestioning kindness and saving my skin, the generous stranger who changed my flat tire on the road out of Rae one snowy night after bingo. For camaraderie, commiseration, and co-celebration, the Circumpolar Students' Association Executive 2004-2005. For financial support, the Social Sciences and Humanities Research Council, the Alberta ACADRE Network, the Province of Alberta, and the Northern Science Training Program (Indian and Northern Affairs Canada). And finally, for the countless hours of love, patience, and support: all of my friends and family—especially Bradley, Melissa, Mom and Bill. I couldn't have done it without you!

TABLE OF CONTENTS

CHAPTER 1: Background and Rationale ...1
- Research in Northern Communities ...1
- What Might the Web Have to Offer? ...3
  - Participatory Health Research Using the Internet ...3
  - Advantages ...4
  - Disadvantages and Ethical Issues ...7
  - Needs for Further Research ...11
- Network North: A Unique Research Opportunity ...13
  - Background ...13
  - Objectives ...14
  - A Human Ecological Perspective ...15

CHAPTER 2: Methods ...17
- Introduction ...17
- Semi-Structured Interviews ...19
- Community Fieldwork ...25
  - In-Person Observation ...26
  - On-line Observation ...27
  - Final Interviews ...27
- Ethical Considerations ...29
  - Political Context ...29
    - Design ...29
    - Conduct ...33
    - Implications ...35
  - Informed Consent, Privacy and Confidentiality ...36

CHAPTER 3: Analysis and Discussion ...39
- Introduction ...39
- Analysis ...39
  - Methods ...39
  - Major Findings ...41
    - Using the Technology ...41
    - Advantages ...42
    - Disadvantages and Barriers ...42
    - Ethical Issues ...44
    - Summary ...46
- Discussion ...48
  - Understanding Community ...48
  - Understanding Disparity ...49
  - Understanding Priorities ...56
  - Roles and Responsibilities ...60
- Conclusions ...65

REFERENCES ...68

APPENDIX A: Service Provider Interview ...86

APPENDIX B: Community/Researcher Interview ...87

APPENDIX C: Student Survey ...88

LIST OF TABLES

Table 1: Initial Interview Participants ...20

Table 2: Final Interview Participants ...28

CHAPTER 1: BACKGROUND AND RATIONALE

Research in Northern Communities

With pressing issues such as natural resource development directly affecting northern communities, research continues to play an important role in understanding and mediating the effects of these issues on the health and well-being of community members and their environments. In response to the ongoing development of the Mackenzie Gas Project, for example, a wide range of both quantitative and qualitative research is currently taking place throughout the Northwest Territories, including everything from technical engineering studies and environmental impact assessments, to gathering Traditional Knowledge from community members, and attempting to assess "the effect of the project on local communities" (Mackenzie Gas Project, 2005).

At the same time, however, northerners have been increasingly asserting their autonomy and authority over research processes taking place in their communities. As Stager (1994) writes, many northerners have expressed their desire

> that research and researchers should be responsive to the needs and priorities of northerners, that northerners should benefit both socially and economically from research, that people have a right to know about and have a say in what researchers are doing in their communities, and indeed a right to participate in research, or not to consent to it, as they choose. (p. 65)

This autonomy and authority has been legally strengthened by the ongoing settlement of land claims agreements, which have meant that "a substantial portion of the North is no

longer Crown land but Inuit and Dene land," with some agreements including "specific requirements on the conduct of research" (Stager, 1994, p. 65). As a result, territorial legislation requires that all persons conducting scientific research in the Northwest Territories, the Yukon Territory, or Nunavut consult with and obtain the consent of all appropriate community organizations prior to beginning any research (Aurora Research Institute, 2004; Nunavut Research Institute, 2004; Yukon Heritage Branch, 2001). In addition, experienced researchers recommend that local knowledge contributions be included at all stages of research (ACUNS 1998; U.S. Interagency Arctic Research Policy Committee; 1995), along with a willingness to reconcile research questions and scientific knowledge with this local knowledge (Kaufert, et al., 1999). Perhaps not surprisingly then, participatory methodologies are the most frequently recommended strategies for researching with northern communities (Dene Cultural Institute, 1993; Kaufert, et al., 1999; Ryan & Robinson, 1990). While levels of participation may vary, ranging from ongoing cooperation (Dene Cultural Institute, 1991; U.S. Interagency Arctic Research Policy Committee, 1995) and consultation (ACUNS, 1998), to community capacity building (Council of Yukon First Nations, 2000) and control of data analysis and dissemination (Alaska Native Knowledge Network, 2001; O'Neil, et al., 1993), it has become increasingly clear that "[r]esearchers will have to change their expectations of what constitutes research itself, and its output and productivity" (Stager, 1994, p. 68).

Implementing this change through participatory methodologies in northern communities, however, presents significant challenges to both researchers and community members. Most often characterized as cyclical, iterative, and reflective (Cameron, et al., 2000;

Lindsey & McGuinness, 1998; Roberts & Dick, 2003), participatory research processes can be long, intense and difficult (Gibbon, 2002), as they may require several rounds of meetings and consultations, often before the actual 'research' begins, requiring "additional personnel and financial resources for both communities and researchers" (Stager, 1994, p. 68). In this context, the potential advantages of web-based data collection for qualitative health research in northern communities begin to become apparent.

What Might the Web Have to Offer?

Participatory Health Research Using the Internet

Although the Internet has more often been used for collecting quantitative data (Cotton, 2003), qualitative researchers are also increasingly embracing this method, particularly for enhancement of traditional qualitative methods, such as surveys (Eaton & Struthers, 2002; Fleitas, 1998; Im & Chee, 2004; Shields, 2003), focus groups (Burton & Bruening, 2003; Cooke & Rule; 2001; Moloney, Dietrich, Stickland & Myerburg, 2003) and interviews (Olivero & Lunt, 2004; Fleitas, 1998). Importantly, a great deal of work in this area has already come from health care fields, particularly psychology (Barry, 2001; Childress & Asamen, 1998; Nosek, Banaji & Greenwald, 2002; Rhodes, Bowie & Hergenrather, 2003) and nursing (Cotton, 2003; Im & Chee 2001, 2004; Lakeman, 1997; Moloney, et al., 2003). Although very few studies have been published using these methods in a specifically participatory context, qualitative researchers have noted a number of potential advantages associated with this method that support its potential use in participatory health research. At the same time, however, the studies also indicate that

a number of serious ethical issues can arise from its use, and that further research is needed with specific regard to these issues.

Advantages

A fundamental tenet of participatory research processes is equitable mutual collaboration between researchers and research participants (Argyris & Schön, 1991; Boog, 2003; David, 2002; Dickson & Green, 2001; Gibbon, 2002; Lax & Galvin, McTaggart, 1998; Reardon, 1998). In their use of qualitative methods, participatory researchers therefore look for ways to minimize the distance between researcher and researched (Small, 1995), and to encourage the active participation and feedback of participants as much as possible. Evidence from on-line focus groups, surveys, and interviews indicates that using the Internet to conduct qualitative research helps to facilitate this process in a number of ways.

Several researchers suggest, for example, that on-line research participants may feel empowered by their ability to remain relatively anonymous, as when compared to offline surveys and in-person interviews, they appear to be less inhibited and more open in their responses (Bellini & Vargas, 2003; Eaton & Struthers, 2002; Fleitas, 1998; Moloney, et al., 2003; Olivero & Lunt, 2004; Robinson, 2001; Shields, 2003), particularly in their willingness to provide feedback on the research process (Barry, 2001; Cooke & Rule, 2001; Im & Chee, 2004). Suggested reasons for the increased depth and disclosure of these responses include the lack of obvious visual markers of physical ability and gender, racial, and socio-economic status in text-based on-line discussion groups (Burton &

Bruening, 2003; Maczewski, Storey, & Hoskins, 2004; Olivero & Lunt, 2004), and relative convenience of on-line research when compared to traditional methods. Because it can allow for research participation at a time and pace that is controlled by the participant, on-line research can help to include those who would otherwise be excluded due to barriers such as geographic isolation (Burton & Bruening, 2003; Eichhorn, 2001; Fleitas, 1998; Lakeman, 1997; Olivero & Lunt, 2004) and time constraints (Cooke & Rule, 2001), while also allowing increased time for participants' self-reflection (Lakeman, 1997; Shields, 2003; Salmon, 2002). This combination of relative anonymity and convenience has already been noted as particularly advantageous for physically disabled children (Fleitas, 1998), minority students (Shields, 2003), and autistic persons (Brownlow & O'Dell, 2002). As a result, several researchers have concluded that using the Internet to conduct qualitative research may connect researchers with populations who are otherwise difficult to access (Brownlow & O'Dell, 2002; Sixsmith & Murray, 2001), and allow for more frank discussions of sensitive topics (Binik, Mah, & Kiesler, 1999; Burton & Bruening, 2003; Rhodes, Bowie, & Hergenrather, 2003). These are important advantages for participatory researchers who are often directly concerned with addressing the (sometimes politically sensitive) needs of marginalized populations (Reardon, 1998). Finally, some researchers indicate that this accessibility may be further extended by using non-textual forms of on-line communication, such as video-conferencing (Childress & Asamen, 1998; Im & Chee, 2004; Lakeman, 1997; Mustanski, 2001) and voice-command technology (Rhodes, et al., 2003) to conduct research. While this may compromise advantages associated with anonymity, it may also allow for the participation of individuals for whom textual literacy is an issue.

As introduced above, two of these challenges—geographic isolation and time constraints—are of particular importance with regard to research in Northern Canada. The Northwest Territories, for example, has a total population of approximately 41, 872 people, spread out over some 1, 183, 085 km^2 (Government of the Northwest Territories, Bureau of Statistics, 2004a, p. 2), resulting in large travel expenses for researchers, and both financial and human resources costs for hosting communities. Stager (1994) insists that "research planners must build these elements into research programs at the outset, and funding agencies must recognize and provide for these additional costs" (p. 68). This issue is perhaps most comprehensively discussed by the Inuit Tapirisat of Canada (1993), who draw attention to the additional strain on the human and financial resources of researchers, northern Aboriginal communities, funding agencies, and central regulating agencies implied by the application of participatory methodologies. The Inuit Tapirisat ask, "What kind of infrastructural support will be required for researchers and communities, and who should be responsible for providing it?" (p. 11). These factors, along with the fact that home access to the Internet is now available "in approximately half of NWT communities" (Daniels, 2004, p. 59), suggest that the Internet might begin to provide a partial answer to that question.

Secondly, and perhaps most importantly, there is also evidence to suggest that using the Internet in qualitative research can help to promote community empowerment (Bier, Sherblom, & Gallo, 1996; Forte, 2004; Hampton, 2003; Mehra, Bishop, Bazzell, & Smith, 2002), an important and explicitly stated goal of many participatory research

projects (Cameron, Hayes, & Wren, 2000; David, 2002; Hondagneu-Sotelo, 1993; Lax & Galvin, 2002; Petras & Porpora, 1993; Simonson & Bushaw, 1993; Small, 1995), as well as for northern communities themselves, who are increasingly demanding that outside researchers meaningfully "engage the realities of increasing self-determination" (Kaufert, et al, 1999, p. 143). Hampton (2003), for example, conducted an ethnography of a developing suburb called Netville, where free Internet access was provided as an incentive for purchasing homes. In this study, Hampton also observed that the use of computer-mediated-communication not only strengthened community ties, but also became a powerful and cost-effective tool for community action, which took place in both on- and off-line forms. Forte (2004) reported similar conclusions in his work with the Santa Rosa Carib Community in Trinidad and Tobago. Originally hired by the community to create a promotional web site, Forte continued to collaborate with the community, expanding the site into an on-line platform used by community members to pursue "offline goals," and as a "point of entry into on-line research and widened collaboration" (p. 223). Although not using the Internet primarily for data collection, these examples clearly demonstrate the Internet's potential as a catalyst for community capacity-building, a fundamentally valued outcome for many participatory researchers (Cancian, 1993; Chataway, 1997; Dickson & Green, 2001; Gibbon, 2002; Lindsey & McGuinness, 1998; Pain & Francis, 2003; Reardon, 1998).

Disadvantages and Ethical Issues

Given these potentially powerful advantages, however, employing the Internet for data collection and dissemination in participatory research also raises a number of important

methodological difficulties and ethical issues, requiring serious and critical examination. First, because of the relative anonymity in text-based communications discussed above, researchers collecting data from on-line communications often cannot be entirely certain of who they are communicating with, and attempts at confirming identity (and therefore informed consent) may compromise that anonymity and the advantages it provides (Binik, Mah, & Kiesler, 1999; Delorme, Zinkhan, & French, 2001; Im & Chee, 2001; Mustanski, 2001; Roberts, Smith, & Pollock, 2004; Sveningsson, 2004). Second, even when respondents' identities can be confirmed, because respondents and researchers do not share the same physical space, data from visual or other non-textual behavioural cues (Binik, et al., 1999; Greenbaum, 1997; Burton & Bruening, 2003; Maczewski, et al., 2004; Olivero & Lunt, 2004) and the respondents' environmental context (Cooke & Rule, 2002; Eaton & Struthers, 2002; Im & Chee, 2001; Mustanski, 2001) are lost. Loss of this information can make it difficult for the researcher to determine and appropriately respond to any crisis situations that may emerge (Keller & Lee, 2003; Rhodes, et al., 2003), thereby possibly increasing the potential for their research to cause harm. Third, regardless of whether or not anonymity and informed consent can be verified, an additional concern is always present regarding the privacy of participants' responses and personal information. Researchers are therefore careful to warn that despite improving technology for safeguarding on-line communications, the potential for third-party access to on-line data (and therefore privacy violation) is always present (Binik, et al., 1999; Brownlow & O'Dell, 2002; Ess & Jones, 2004; Delorme, et al., 2001; Forte, 2004; Im & Chee, 2004; Maczewski, et al., 2004; Moloney, et al., 2003; Nosek, Banaji, & Greenwald, 2002; Pittinger, 2003; Rhodes, et al., 2003).

An additional methodological and ethical issue concerns the lack of equitable access to the equipment and technical skills necessary for effective Internet use. Currently, access to these skills and equipment is overwhelmingly limited to those with relatively high education and income levels (Binik, et al., 1999; Cotton, 2003; Keller & Lee, 2003; Mustanski, 2001; Nosek, et al, 2002; Pittinger, 2003), who tend most often to be young, male, and White (Im & Chee, 2001; Moloney, et al., 2003; Rhodes, et al., 2003; Robinson, 2001). Although as previously discussed, interactions through qualitative Internet research may prove empowering, researchers considering this method need to be aware of its potential to exclude older, female, and non-White populations. A potential solution to this problem is to use research to introduce Internet technology and skills to communities where they may not already be present, as some researchers have already done (see for example, Bier, et al, 1996; Forte, 2004, Hampton, 2003; Kuhmunen, 2003), or are beginning to do (Mehra et al., 2002; Rodriguez, 2003). An additional ethical issue is raised in these situations, however, with regard to the researcher's long-term responsibility to these communities. Bier et al. (1996), for example, provided six low-income Florida families with free Internet access for a limited period, in order to study their patterns of use and personal experiences with the technology. Throughout the study period, participants gained confidence in their ability to learn and teach others successfully and formed an important network of friendship and support, dramatically improving their self-perceptions and overall quality of life. Although participants entered the study knowing their Internet access would eventually be discontinued, Bier et al. ultimately felt that they had become dependent on this access, and so could not ethically

refrain from providing it, even after their study was finished. At the time of their paper's publication, they were continuing to provide Internet access to study participants.

Adding complexity to these issues is the fact that although several researchers have suggested ethical guidelines for Internet research (Binik, et al., 1999; Childress & Asamen, 1998; Flicker, Haans, & Skinner, 2004; Brownlow & O'Dell, 2002; Ess & Jones, 2004; Maczweski, et al., 2004), none are yet available that are universally agreed upon or enforceable. As a result, important questions with regard to ethical Internet research remain unanswered. For example, researchers remain deeply divided as to whether forums of on-line communication are considered public or private spaces (Ess & Jones, 2004; Eysenbach & Till, 2001; Keller & Lee, 2003; Lawson, 2004; Roberts, Smith, & Pollock, 2004; Sixsmith & Murray, 2001). As a result, there is no consensus regarding whether informed consent is even necessary for Internet-based research (Flicker et al, 2004), or if it is necessary, which members should provide informed consent in group settings (Keller & Lee, 2003). In addition, for text-based interactions, it has also not yet been determined if on-line discussions should be considered texts, which may fall under copyright protection laws, or casual speech, which do not (Lawson, 2004). Finally, even if these interactions are considered copyrighted speeches, the question of who would own those copyrights (the group or each individual contributor) has not yet been resolved (Brownlow & O'Dell, 2002; Lawson, 2004; Roberts et al, 2004).

Needs for Further Research

A close reading of the literature surrounding qualitative research using the Internet reveals several potential areas for further research, two of which are particularly relevant to this study. First, in addition to the lack of consensus regarding ethical standards for conducting Internet research, there is a dearth of ethical examination of potential issues from the perspectives of non-European or Euro-American academics and community members. Of all of the previously cited sources of suggested ethical guidelines, the only group to discuss this issue in depth is the Association of Internet Researchers (AoIR), who assert that "efforts to respond to ethical concerns and resolve ethical conflicts must take into account diverse national and cultural frameworks" (Ess & Jones, 2004, p. 29). While they make this important point, however, their discussion is limited to a comparison of American (United States) and European approaches to Internet research ethics, not considering the perspectives (and potentially different concerns) of Third World, Aboriginal, or even Canadian populations. In the case of Aboriginal communities, Cree scholar Greg Young-Ing (2003) argues that that a unique and detailed ethical examination at the community level is especially important, as when considering the use of any new technology, Indigenous peoples do so adhering to two important principles:

> 1) that incorporating new ways of doing things should be carefully considered in consultation with Elders, traditional people and community; and 2) if it is determined that a new technology or institution goes against fundamental cultural values and/or might lead to negative cultural impact, then in should not be adopted. (p. 16)

Thus before outside qualitative researchers begin to engage in on-line research with Indigenous communities, members of these communities must have the opportunity to raise questions regarding the ethical issues surrounding the use of this technology, to be openly discussed and debated by all parties involved.

A second area for further research surrounds the role of technical service providers as third parties in Internet-based research. Sources in the literature often acknowledge or imply the frequent need for social scientists lacking advanced computing skills to consult with information technology specialists in the design and application of their on-line research tools (Cotton, 2003; Im & Chee, 2004; Moloney et al., 2003). While these researchers often acknowledge the potential expense and inconvenience associated with these consultations, they have yet to explore the question of whether the involvement of these third parties may raise additional ethical issues. While the literature does not suggest that information technologists would necessarily act unethically, their possession of specialized knowledge and skills essential to the successful design and implementation of Internet research, as well their position as the architects of bridging technology between researchers and communities, endows them with a considerable amount of power in the research process. Therefore, because participatory research involves cogenerative learning (Freire, 1993) and reflection (Cameron, Hayes, & Wren, 2000; Roberts & Dick, 2003) by all parties involved, information technologists need to be included as equally responsible partners in its processes.

Network North: A Unique Research Opportunity

Background

Although in its early stages, the current development of a northern research initiative called Network North has provided an excellent case for study regarding ethical and methodological issues related to the use of the Internet in participatory research with northern, primarily Aboriginal, communities. Network North was envisioned as an Internet-mediated health research and information dissemination network, and is currently under development between a number of institutional partners, including the Canadian Circumpolar Institute, the University of Alberta, the University of British Columbia, the Alberta ACADRE Network, and the Aurora Research Institute. Confirmed community partners include the Dogrib Rae Band and the Dogrib Treaty 11 Council, while interest has also been expressed by Deline in the Northwest Territories, the North Peace Tribal Council in Northern Alberta and British Columbia, Sanikiluaq, Nunavut, and Nunavik, Quebec. Conceived in direct response to the needs of northern Aboriginal communities, Network North's objectives are to (a) provide a network through which communities with similar research experiences can share and enhance their stories and results through digital communication; (b) to develop and evaluate a knowledge profile model on northern community research employing multimedia technology; (c) to train academic and community researchers with this new model; and (d) to produce new knowledge about northern community health and environmental security to inform national policy. Guiding these objectives will be the core participatory principles on which Network North aims to be based, that: (a) research is relationship based; (b) all research partners have an equal voice; (c) the knowledge of all research

partners is valid and complementary, and (d) all partners share in the responsibility to do good research. Within this larger framework, the focus of my research has been to initiate discussions and gather qualitative data regarding the salient ethical issues related to the use of the Internet as a research and dissemination tool, as they are envisioned by key informants from the community, technical service provider, and outside researcher parties to this collaboration.

Objectives

Attempting to respond to the context of Network North's development and the needs for further research discussed above, my research addresses three objectives. First, drawing on key informants from within Network North's partnering groups, I aimed to initiate and explore discussion regarding potential ethical issues surrounding the use of the Internet as a participatory research and dissemination tool in northern Aboriginal community-based research. To meet this objective, qualitative data, in the form of semi-structured interviews, participant observation, and documentary research was collected from community members, technical service providers, and outside researchers involved in or directly affected by this collaborative project. Having collected this data, the second objective was then to comparatively analyze and critique this data with reference to previous studies, searching for common ethical principles and areas of potential ethical conflict. Once this analysis was completed, my third and final objective was to report on this analysis, and any recommendations that emerge for further research in this area.

A Human Ecological Perspective

Finally, guiding both the design and analysis employed in this study is a human ecological perspective, particularly as influenced by Bronfrenbrenner (1994), Sontag and Bubolz (1988), and Bubolz and Sontag (1993). Defined as "the scientific and holistic study of human beings, their environments, and human-environmental interactions" (Westney, Brabble, & Edwards, 1988, p. 129), its core theoretical concept is the human ecosystem, comprised of dynamic and interrelated natural, human constructed, and human behavioural environments, in which human beings interact and reciprocally influence both these environments and one another (Sontag & Bubolz, 1988). From this perspective, Network North can be conceived of as a human constructed environment, being co-designed by northern communities, technical service providers, and outside researchers for the pursuit of specific research objectives. Employing Bronfrenbrenner's (1994) conception of human environments as sets of "nested structures" (p. 1645), each party brings to this new environment its own values, patterns, and actions (*microsystems*), which interact with one another to mutually influence its development as a *mesosystem*, or system of microsystems. Within this emerging mesosystem, the Internet is positioned as one of the many *exosystems*, or linkages and (research) processes, emerging within the developing mesosystem.

In addition to providing a concrete theoretical structure in which to position such an interactive environment, a human ecological perspective encourages internal ethical exploration, because it explicitly acknowledges the interplay between cooperative and competitive goal-oriented components within human interactions (Bubolz & Sontag,

1993); seeking to understand the interrelationships among the values, knowledge, education and practice these interactions employ (Sontag & Bubolz, 1988). Finally, human ecology theory is also "prevention-focused rather than crisis-oriented" (Westney et al., 1988, p. 133). Thus this perspective encourages not only the exploration of human environments and ethical issues, but also the undertaking of such exploration in the early stages of their development, ideally before potential conflicts emerge. What my project has explored, then, are the ethical issues at play within this newly emerging mesosystem of Network North, specifically as they relate to its potential use of the Internet as an exosystemic research process. The details of that exploration are discussed in the following chapter on methods.

CHAPTER 2: METHODS

Introduction

According to Van Maanen (1983), qualitative researchers

> claim to know relatively little about what a given piece of behavior means until they have developed a description of the context in which the behavior takes place and attempted to see that behavior from the position of its originator. (p. 10)

As this study aimed to understand the salient ethical issues related to the use of the Internet as a health research and dissemination tool from the potentially differing *positions* of northern community members, technical service providers, and outside researchers, such a methodology, "based on methods of data generation which are flexible and sensitive to the social context in which data are produced" (Mason, 1996, p. 2), was especially appropriate. Therefore, while I strove to conduct my research "*systematically and rigorously*," like other qualitative researchers, I also made decisions "on the basis not only of a sound research strategy, but also of a sensitivity to the changing contexts and situations in which the research [took] place" (Mason, 1996, p. 5).

The original design for this project was a case study research strategy guided by a participatory research process. Adapted from Yin (1994) and Creswell (1998), this project was an *exploratory* case study of Network North, with focused and *embedded* analysis designed to illustrate the topic of ethical web-based research in northern Aboriginal communities in a primarily *descriptive* mode. As case studies necessarily involve the collection and triangulation of multiple sources of data (Creswell, 1998; Keen

& Packwood, 1996; Yin 1994), data were collected in the form of semi-structured interviews (with community, research, and technical service personnel), personal observations (conducted at Chief Jimmy Bruneau Regional School, Rae-Edzo, NT), and documents (academic and grey literature; websites; all collected throughout). Yin (1994) delineates five essential components of exploratory case studies (p. 27), which I applied to my proposed research as follows: the study's *purpose* was to identify and analyze the salient ethical issues regarding the use of the Internet as a research and dissemination tool in northern Aboriginal communities, as perceived by community, technical service, and research partners within Network North; while the central *questions* it sought to answer were: 1) What are these salient ethical issues? 2) (How) are they similar or different among members from different parties? To address Yin's (1994) remaining elements, the *units of analysis*, the *logic linking data to purpose*, and *criteria for interpreting the findings*, I turned to a participatory and reflexive research process. Throughout this process, I aimed to seek input from both participants and their data in developing additional guiding subquestions (Creswell, 1998), and data collection strategies, to maximize the study's validity, relevance, and benefits to all participants involved. Marshall and Rossman (1999), however, remind us that "design flexibility is a crucial feature of qualitative inquiry," and "urge the researcher to think of the proposal as an initial plan" (p. 17). More specifically, they go on to state that

"this plan is a *guide*; it is a tentative road map that will most likely undergo some modifications as data are collected and analyzed and as new patterns for more focused data collection become apparent" (p. 179).

This guide, as well as its modifications and new patterns, are the focus of discussion in this chapter, outlining the methodological approach to this project.

Semi-Structured Interviews

After completing the initial literature reviews discussed in the first chapter of this thesis, the second phase of this project consisted of semi-structured, audio tape-recorded interviews with participants selected through a mixture of two sampling methods. First, through expert sampling, I attempted to assemble "a sample of persons with demonstrable experience and expertise" in the area of providing and working with information technology in northern communities (Trochim, 2001, p. 57). Then, through snowball sampling, I asked these and subsequent participants to recommend "others they know who also m[et] the criteria" for my study (Trochim, 2001, p. 58). At this stage, four interviews were conducted with five participants (Table 1). Two flow-charts were used to guide the interview process, one designed for interviews with technical service providers (Appendix A), and the other designed for interviews with both researchers and community members (Appendix B). These charts were not followed literally, but rather used as topical and conceptual guides, adapted according to the each participant's response style and experiences. A preliminary thematic analysis was conducted, the method and results assessed through peer debriefing with my supervisor, Dr. Nancy Gibson. Major themes were noted if they occurred in two or more interviews.

Table 1

Initial Interview Participants

Interview No.	Participant(s)	Experience	Sampling Method	Category
1	Andrew Applejohn	Director, Aurora Research Institute	Expert	Technical Service Provider
	Darrell Fraser	Webmaster, Aurora Research Institute/Aurora College	Snowball	Technical Service Provider
2	*Rachel	Instructor and Researcher, Aurora College	Snowball	Researcher
3	Anne Grieve	Independent Researcher	Snowball	Researcher
4	Michael Corbett	Executive Director, Look North	Expert	Technical Service Provider

Note. Name marked with an asterisk (*) is a pseudonym.

Before these interviews were completed, however, a number of conceptual boundaries that I had perceived as important in the design phase became slippery and began to lose

their meaning, causing important shifts in the direction and focus in my study. The first of these concerned the nature of my research question itself: *what are the salient ethical issues regarding the use of the Internet as a health research and dissemination tool in northern Aboriginal communities*? In keeping with a qualitative focus on context, the interview guides were designed to elicit information not only on potential ethical issues, but on the advantages and disadvantages/barriers, and strategies for overcoming barriers and resolving ethical issues participants saw as relevant to using the Internet to conduct research in northern Aboriginal communities. As the interviews progressed, however, it became apparent that for many participants, some of these essentially methodological issues were impossible to separate from ethical issues. This is demonstrated, for example, by Rachel, discussing her concern over lack of technological skills at the community level, an issue that would continue to resurface as both a barrier and an ethical concern by others throughout this project:

> I mean use of the Internet, seems to be, possibly, an esteem thing. I'm not even sure if people can or cannot use the Internet. I mean I'm not sure if you could even look at that, and there's those people who can't use it, because they're afraid to or, because someone hasn't taught them how to play solitaire so they know how to use the mouse.

Taking this relationship into account then, the research question addressed by this project is more accurately described as follows—*What are the salient ethical* ***and methodological*** *issues regarding the use of the Internet as a health research and dissemination tool in northern Aboriginal communities*—as in the context of my study,

an investigation involving communities by and large just beginning to adopt internet use—these issues proved to be intimately intertwined.

A second instance of this conceptual slippage also began to occur at this stage, disturbing my preconceived notions of who should be included in the study. As stated in Chapter 1, I had originally planned to interview participants directly involved in Network North as community members, technical service providers, and outside researchers. As these interviews progressed, however, I began to find this sampling scheme limited and problematic. More specifically, I was again reminded of the importance of context by a recurring theme that began to emerge in the first four interviews (and would continue throughout)—that of a lack of access to adequate IT equipment at the community level. The emergence of this theme as an ethical issue was not surprising in itself, given its frequent mention in recent literature (Binik, et al., 1999; Cotton, 2003; Im & Chee, 2001; Keller & Lee, 2003; Moloney, et al., 2003; Mustanski, 2001; Nosek, et al, 2002; Pittinger, 2003; Rhodes, et al., 2003; Robinson, 2001). Its relationship to the context and potential development of Network North, however, was, as demonstrated by the following interview excerpt:

> Q: Do you see a role for institutions or government in deciding how to resolve these issues?
>
> A: All that I could see is that, specifically, within the Territories, is we don't have institutions or government or organizations that know how to help the

communities in the first place, or there is no funding for a lot of it—no infrastructure for that…

Clearly, an important political dimension was perceived to exist in relation to these issues—one that served as reminder that Network North itself not only *provided* a context for this study, but also *existed within* a complex and dynamic social and political context itself. Understanding how the Internet could function as a research tool within Network North therefore also meant gaining some understanding of its place in this broader context. To do that, I had to stray from my original plan and speak to someone completely outside of the project itself but with knowledge and experience of that political context, particularly as it related to finances and infrastructure for technology—my fifth interview participant.

Finally, and perhaps most importantly, a third change in the direction and focus of this study also resulted from the conduct and analysis of these initial interviews, though it represented more of an instance of "new patterns for more focused data collection becom[ing] apparent" (Marshall & Rossman, 1999, p. 179) than a conceptual shift. Running as an undercurrent throughout each of these interviews were stories about northern youth, particularly as their interest in and use of information technology related to potential ethical issues. Darrell, a technical service provider, related the following example:

…We did a school project one time—and this was quite a while ago—we toured the schools and everything …We took a lot of pictures and everything, and we

were actually hoping to do something with it. A product we could give back to the school, or, you know, if the students would like to see pictures on the Internet that they could grab. But again the issue came out of, I guess, of the properness of actually putting something like that on the web, or actually doing something with it, so we really had to step back…Actually it was a student that in a certain community had concerns about the picture we took … so I guess that kind of started this thought process. Well, you know, we're kind of just barging ahead with this, should we actually really just stop and realize, you know, the consequence of what we're doing. That's where we kind of stepped away.

In that instance, a young person was cited as raising awareness of an important ethical issue. In another, however, a researcher also expressed concerns regarding the ability of youth to learn IT skills quickly—sometimes outpacing adults attempting to teach them and supervise their learning:

> We had one class, quite a few years ago, where they were in a computer lab, and they were able to hack into the system and do stuff to each other's computer work, from across the room. I mean, I can't do that. So these youth were way out there … But that's what the youth do—that's a challenge for them, and they're smart.

Given these and other similar examples, along with the fact that "[y]oung students form a large percentage of the users at public access sites" in Northwest Territories communities (Daniels, 2004, p. 59), these preliminary data suggested that a key to understanding

ethical issues in relation to Internet usage in northern Aboriginal communities would be found in studying and understanding the activities of those communities' most active and experienced users—their youth.

Community Fieldwork

In order to observe and interact with some of these youth in their own context, I then spent a four weeks in the predominantly Dogrib Dene community of Rae-Edzo, Northwest Territories. Located approximately 110 km north-west of Yellowknife, the two communities of Rae and Edzo combine to form a population of approximately 1,895 individuals, with 1,752 identifying as Aboriginal, and 143 as non-Aboriginal (Government of the Northwest Territories, Bureau of Statistics, 2004b). Chief Jimmy Bruneau Regional School (CJBS) Principal, Ms. Rita Mueller, along with the Dogrib Community Services Board, generously agreed to host me as a guest in the school dormitory, from February 14 to March 15, 2005.

The school proved to be an especially effective research site for a number of reasons. First, as an institution with approximately 358 students enrolled in kindergarten to grade 12, CJBS not only serves students from Rae and Edzo, but from communities throughout the Dogrib Region, such as Gameti and Whati as well (CJBS, 2004). Second, although at-home Internet access is fortunately available throughout Rae-Edzo, CJBS was one of the few places within the community to have relatively high-speed cable access, as opposed to the slower, dial-up connections. Thus in addition to observing students' Internet usage, I was also able to get a brief glimpse into that of other associated community members,

some of whom relied completely upon the school for their connection to the Internet. Finally, through my affiliation with CJBS, I was also able to gain access to the Dogrib Intranet, a regional web-based communications system, through which I was also able to conduct valuable on-line observations.

In-Person Observation

Due to daily fluctuations in students' attendance, teachers' lesson plans, special events such as sports tournaments and assemblies, and additional research opportunities, daily in-person observational patterns varied in both length and location, primarily alternating between the two locations within the school where both students and teachers regularly accessed the Internet—the computer lab and the library. On average, two to three hours per school day were spent in the computer lab, mainly directly observing (Trochim, 2001, p. 161) but also occasionally assisting with regularly scheduled computer classes (grades nine to 12) and visits to the lab by students in other classes (grades seven to 12), as well as observing and interviewing the computer instructor. An additional three to seven hours per week were also spent in the library, both in direct observation of both students and staff, and as a "participating observer" (Bernard, 2000, p. 317) and volunteer assistant to the librarian. Occasionally, less frequent activities, such as the use of the Internet through a data projector to teach an eighth grade science class, were also observed when such opportunities arose. Finally, as a supplement to these observations, a short survey was also conducted with a small sample (not representative) of senior high school students (Appendix C).

On-line Observation

When not observing students in person, as mentioned above, I also conducted on-line observation, via my access to the Dogrib Intranet, mainly accessible by teachers, students, health care workers, and local government employees throughout the Dogrib Region. Through this network, I had access to a local email account, message boards for both students and staff, as well as live, synchronous chat. This was especially helpful at CJBS, as the system was frequently used for communication by both staff and students, and was locally administered by the computer instructor. Through my use of this system, as well as my ongoing contact with one of its administrators, I was therefore able to construct a picture of both the system as it was being used within the community, as well as the context in which administrative decisions were made about its daily operations. Importantly, it was also through this system that I was able to contact several community members and arrange for my final round of interviews, which would serve to cap off my community fieldwork.

Final Interviews

While in Rae-Edzo, I also conducted 12 additional interviews. Seven of these were informal interviews with six staff members and one student at CJBS, forming an integral supplement to the in-person and observational data being collected, while the additional five were formal interviews with other community members (Table 2). Aside from the students whom I had observed, interviewed, and who had completed my survey, the remaining interview participants, although long-time community members, were all non-Aboriginal. Two Aboriginal adults were contacted, but did not participate. After returning

to Edmonton I conducted my final interview, with an adult Aboriginal member from a different northern community.

Table 2

Final Interview Participants

Interview No.	Participant	Experience	Sampling Method	Category
5	*Jennifer	Community Health Care Worker	Expert	Community Member
6	*Donna	Community Health Care Worker	Snowball	Community Member
7	Anna Beals	Community Health Administrator	Snowball	Community Member
8	Arita de Boer	Community Health Administrator	Snowball	Community Member
9	*David	Teacher/Researcher	Expert	Researcher
10	*Sharon	Community Member/IT User	Expert	Community Member

Note. Names marked with an asterisk (*) are pseudonyms.

Ethical Considerations

Political Context

Mason (1996) writes,

> Qualitative research should involve critical self-scrutiny by the researcher, or active *reflexivity*. This means that the researcher should constantly take stock of their actions and their role in the research process, and subject these to the same critical scrutiny as the rest of their 'data.' (pp. 5-6)

In addition to the reflection on methodological strategy presented above, this reflexivity is also extremely important with regard to ethical conduct, which in qualitative research, necessarily includes a "regard to its political context" (Mason, 1996, p. 6). This context can become particularly charged in research that involves Aboriginal communities, as researchers working with these communities are increasingly being called to recognize that "all research is implicitly political" (O'Neil, et al., 1993, p. 229); and to understand, as Menzies (2001) writes, that "to deny the colonial legacy by not adapting our research projects to accommodate Aboriginal concerns is to participate in the colonial project itself" (p. 22). As such, discussion of this study's ethics cannot be considered complete without including a discussion of the political considerations that helped to shape both its design and conduct.

Design.

My first investigation into this political context took the form of an extensive review of current literature surrounding ethical research conduct with Aboriginal communities,

particularly in Canada and the north (Brown, in press). Based upon this review, I attempted to construct a research design that would meaningfully reflect (within the limits of this project) the principles of respect (ACUNS, 1998; Alaska Native Knowledge Network, 2001; Bopp, Bopp, Brown, & Lane, 1985; Community Information and Epidemiological Technologies Canada, 2003; CYFN, 2000; Haig-Brown & Archibald, 1996; International Society of Ethnobiology, 1998; National Aboriginal Health Organization, 2002; Menzies, 2001; Weijer, Goldsand, & Emanuel, 1999; U.S. Interagency Arctic Research Policy Committee; 1995) and equitable partnership (American Academy of Pediatrics, 2004; Community Information and Epidemiological Technologies Canada, 2003; Gibson & Gibson, 1999; Kahnawake Schools Diabetes Prevention Program, 1997; Korsmo & Graham, 2002; Macaulay, 1994; Mi'kmaq College Institute, 2000) repeatedly emphasized throughout the literature. For example, while being careful to allow for community input and adaptation of proposed methods, through the Research Ethics Board for the Faculty of Agriculture, Forestry and Home Economics at the University of Alberta and the Aurora Research Institute, I received ethical approval to conduct observations and tape-recorded interviews with adult participants, who could choose to remain anonymous or to be directly personally identified, in accordance with the stated wishes of many northern Aboriginal community members (ACUNS, 1998; Alaska Native Knowledge Network, 2001; Assembly of Alaska Native Educators, 2000; Evans, 2004; McCormick, 1998; Ruttan, 2004; U.S. Interagency Arctic Research Policy Committee, 1995; Weijer, et al., 1999). As demonstrated in Tables 1 and 2 above, pseudonyms are provided to protect the confidentiality of participants who wished to

remain anonymous, while the real names of those who consented to be personally identified have been used.

Importantly, as part of equitable partnership, participatory methodologies were most often recommended when researching with Aboriginal communities (Dene Cultural Institute, 1993; Kaufert, et al., 1999; Mi'kmaq College Institute, 2000; North American Primary Care Research Group, 1998; Ryan & Robinson, 1990), who have increasingly demanded to be active participants in *all* stages of research (American Association of Pediatrics, 2004; Canada, 1993; International Society of Ethnobiology, 1998; Kahnawake Schools Diabetes Prevention Project, 1997; Kaufert, et al., 1999); from inception of research questions to dissemination of results. These methods, however, are also known for being long, intense, and difficult (Cameron, Hayes, & Wren, 2000; Gibbon, 2002; Lax & Galvin, 2002), as well as expensive (Lincoln, 1998). Gibson and Gibson (1999), for example, include among the typical characteristics of successful academic collaborators the ability to "take risk without fear of censure" and to have "time that is protected for research" (p. 111), advantages clearly not accessible to all academic researchers—particularly those at the graduate level. As a result, although a fully participatory research project—involving constant community direction from the very earliest stages—was not feasible, several practical participatory elements were integrated into the design.

Once formal (tape-recorded) interviews were completed, each participant was given either a summary (nine) or a copy of the actual transcript (one) for his/her review;

enhancing not only the participatory nature of this project, but also the trustworthiness of the results, through member-checking. For informal interviews, this process was slightly modified. Only hand-written notes were taken, and participants were given verbatim copies of these notes. Through this exchange, I not only posed any necessary additional questions, but participants then had the opportunity to clarify any points and/or add any comments as they saw fit. Eight of 10 formal participants provided feedback through this process. For one, this process proved to be especially important from an ethical perspective, as he/she had originally consented to be personally identified, but after reflecting on his/her summary decided that he/she would rather remain anonymous (a decision I have respected). Second, before this thesis was submitted, participants were given the opportunity to review a completed draft of the entire document. At this time, they were again invited to raise any objections or provide any additional comments regarding the use of their information, to be included in the final version should they so desire. Third, because communities have expressed the desire not only to participate more fully in the research process, but also to have greater understanding of and control over the dissemination of research results (Alaska Native Knowledge Network, 2001; Community Information and Epidemiological Technologies Canada, 2003; O'Neil, et al., 1993), a presentation will be made at Chief Jimmy Bruneau Regional School, and copies of the completed thesis document will be made available to community organizations as well interested research participants. Fourth and finally, because these participatory research processes tend to be cyclical, iterative, and reflective (Cameron, Hayes, & Wren, 2000; Roberts & Dick, 2003), I also stipulated, when applying for ethical approval, that all of these strategies for data collection and dissemination of results would be open to

negotiation and might therefore change throughout the research process, not only in response to the data, but to the needs of participants' themselves.

Conduct.

In addition to incorporating participatory design elements, I also attempted to express sensitivity to political and social context in response to other recommendations found within the literature, as well as to specific conditions present within the community itself—attempts that provided both methodological and ethical challenges to how this design was actually implemented. First, several sources in the literature point out that successful research with Aboriginal communities is largely based on building interpersonal relationships (Inuit Tapirisat of Canada, 1993; Kaufert, et al., 1999; Menzies, 2001; Ruttan, 2004), and that building these relationships takes time (Gibson & Gibson, 1999; Kowalsky et al, 1996). For this reason, given my limited time in the community, I concentrated most on building relationships with staff and students at the school, where I was most often seen and people had the most time to get used to my presence. Attempting to follow recommendations from researchers with experience in northern Dene communities, such as "[p]articipating in community activities" (Kowalsky et al, 1996, p. 11), I also volunteered at two school-sponsored bingos, as well as in the school library, and took advantage of an invitation to visit the Dogrib Community Services Board.

Second, other sources within this body of literature have also pointed to community frustration with research that has generally lacked culturally appropriate ethical standards

(Haig-Brown & Archibald, 1996), as well as respect for communities' cultural beliefs (Norton & Manson, 1996). With specific regard to northern Dene communities, experienced ethnographer J.A. Goulet (1998) emphasizes that Dene "expect learning to occur through observation rather than instruction," in accordance with their belief that "true knowledge is personal knowledge" (p. 27). As such, he suggests that outside researchers conform to this "pattern of learning by observation, without asking questions" (pp. 31-32), rather than "attempting to establish rapport through talk" which can appear "aggressive" (p. 56). To respect these values, I chose to spend most of my time with Aboriginal community members in quiet observation, rather than aggressively pursuing them to engage in interviews.

Third, I also needed to respect the priority of an extremely important community change that was beginning to take place just as I arrived in Rae-Edzo. On February 15, 2005—one day after my arrival—royal assent was given to Bill C-14: The Tlicho Land Claims and Self-Government Act (Bill C-14, 2005). As a comprehensive land claim for the entire Dogrib Region, the agreement specifies local control and administration of almost every aspect of community life, also promising to provide five million dollars "to train T citizens for jobs in Tlicho Government and other jobs relating to implementation of the Tlicho agreement" (Plainspeak, 2003, p. 23). As the capital of the Dogrib Region, Rae-Edzo is home to the Dogrib Treaty 11 Council, and necessarily serves as the centre of implementation activities. As a result, many potential community 'key informants' were already extremely busy with the ensuing administrative preparations and celebrations. Rather than attempt to interfere during this critical time, therefore, I adopted a

recommendation of the Inuit Tapirisat of Canada (1993) that research "must avoid social disruption," and chose to continue my focus on Aboriginal youth and community health care workers. Of three key Aboriginal contacts recommended to me, I attempted to establish contact with two, one of whom did not respond, and one of whom initially agreed but later declined due to lack of time. The third, a community leader heavily involved in the Tlicho Agreement implementation, I then chose not to contact at all. In order to incorporate a similar perspective, therefore, I conducted my final interview with Sharon, an adult Aboriginal community member from Northern Saskatchewan. Though originally from a different community, Sharon not only met the methodological criteria for participation in my study, but, I felt, was ultimately a more ethical choice, as we had already developed a mutually respectful and trusting relationship through previous contact, and it was relatively easy for her to volunteer her time.

Implications.

Although I collected a great deal of observational data (primarily concerning the youth), as well as interview data (from non-Aboriginal community members), it can be argued that, as was initially the case for Kowalsky et al. (1996), I actually "gained little insight" regarding the rest of the community's views about ethical Internet usage (p. 7). While the choices may have therefore resulted in a methodological disadvantage, from my perspective, they were nonetheless essential from an ethical one. Kowalsky et al. (1996) also write that researchers "must reflect on their motives about working with Aboriginal people," as they will likely be closely evaluated by community members as part of the process of establishing trust (p. 10). Similarly, Sto:lo academic Jo-Ann Archibald (1993)

insists that when attempting to develop respectful research relationships, "it is not wise to try to be someone you are not" (p. 189). Thus while I clearly see the potential importance of my project from a personal and academic perspective, within the context of the community, I was forced to re-evaluate that importance, and to temper my enthusiasm with regard to its implementation.

Informed Consent, Privacy, and Confidentiality

Finally, in addition to the unique and politically charged ethical considerations implied by the setting of this study, more familiar concerns, such as participants' informed consent, privacy, and confidentiality were equally as important to address in an ethical manner. Meaningfully addressing these concerns also required both reflexive judgment and flexibility in research design, in response to both the research method used as well as its participants. For formal interviews, for example, participants indicated informed consent through the use of a written consent form, pre-approved by the Research Ethics Board of the Faculty of Agriculture, Forestry and Home Economics at the University of Alberta. For informal interviews (which were not tape-recorded and served as a more detailed form of observation), however, this form was inappropriate, as it was designed specifically for tape-recorded interviews in which participants could be personally identified, and would likely be directly quoted at length. For informal interviews, however, informed consent was secured verbally and on the condition that participants' would not be personally identified or directly quoted. These participants were also given verbatim copies of interview notes, which included contact information for myself, should they have any questions or concerns.

Even more complexity and variation was experienced with regard to these issues in the context of observation. First, as different types of observations were conducted, different means were used for ensuring participants' consent. For in-class and library observations, which necessarily involved minors, general approval was given by CJBS Principal Rita Mueller, as well as by individual teachers in individual classrooms. In addition, I sent an introductory email to all students and staff, attempting to explain my research in simple terms and inviting discussion of any questions or concerns. For student surveys, however, which served as a supplement to these observations, care was taken to avoid participation of students under 18 years of age. Approval to conduct the survey was first secured from CJBS Vice Principal Tammy Steinwind, and surveys were always administered in the presence of a teacher, who helped to both clarify the purpose of the survey to students, as well as to verify students' ages.

Second, different kinds of observations also implied different expectations for ensuring privacy and confidentiality. During in-person observations, I chose not to note or otherwise refer to any names of individual students. Similarly, I instructed students not to write their names on surveys. Although not specified in my applications to either the University of Alberta or the Aurora Research Institute, these precautions for protecting participants' privacy and confidentiality arose naturally, as reasonable means for minimizing their "potential deception" (Creswell, 1998, p. 125) and therefore any potential harm they may suffer from this research. For on-line observations, however, considerations of privacy and confidentiality were more complex. As noted in Chapter 1,

researchers currently disagree about whether on-line communication takes place in public or private spaces (Ess & Jones, 2004; Eysenbach & Till, 2001; Keller & Lee, 2003; Lawson, 2004; Roberts, Smith, & Pollock, 2004; Sixsmith & Murray, 2001). As a result, the issue of who (if anyone) should provide informed consent for on-line observations is unclear (Keller & Lee, 2003), and no widely enforceable guidelines have yet been produced. Individual researchers, therefore, are left to delineate their own ethical parameters on a case-by-case basis. In this case, I chose to follow the same guidelines I had applied to in-person observations. Whether observing emails, live chat, or posted messages in chat rooms or message boards, I did not write down the names or email addresses of any participants or quote them directly.

CHAPTER 3: ANALYSIS AND DISCUSSION

Introduction

As the most detailed exploration of this study's subject matter, the formal (tape-recorded) interviews conducted form the backbone of its data and analysis, while data from participant observation and documentary analysis are used to triangulate and elaborate upon the major findings from these data. In addition to the original 10 interviews (with three researchers, three technical service providers, and four community members), one informal interview with a community-based technical service provider is treated as a formal interview for analytical purposes, due to its unforeseen length and depth. Analytical methods and findings are reported below, followed by a discussion of their relevance to the initial research question and current related literature.

Analysis

Methods

Interview transcripts were subject to a thematic content analysis, in a manner adapted from the methods of Dey (1993), Rubin and Rubin (2005), as applied to the initial research design (Yin, 1994; discussed in Chapter 2). First, a general set of categories was created from the "rich source" of the research questions themselves, as they were "redefined and reformulated" through the creation of semi-structured interview guides (Dey, 1993, p. 99). This set of categories included: 1) the interviewees' use of the Internet and related technologies; 2) any advantages he/she perceived as emerging from the use of this technology; 3) any disadvantages or barriers he/she perceived about the same (and suggestions for overcoming them); and 4) any ethical issues he/she has

perceived as relevant to the use of this technology (and suggestions for preventing or resolving them). Second, data within each of these categories were then compared, in order "to allow for a more detailed comparison of data organised [*sic*] within a set of sub-categories" (Dey, 1993, p. 96). These sub-categories were created based on the themes, or "major ideas" (Trochim, 2001, p. 165) that emerged through a comparison of "*data units*" (Rubin & Rubin, 2005, p. 202), or meaningful textual excerpts selected from interview transcripts (the primary "units of analysis" for this study, Yin, 1994, p. 27).

These data units were then sorted under the general category headings discussed above by "grouping all of the data units with the same label into a single computer file" (in this case, Microsoft Word), in order to reveal "systematic differences between groups of interviewees on the same concept" (Rubin & Rubin, 2005, p. 208)—the "logic linking" the data to the "purpose" of the study (Yin, 1994, p. 27). Importantly, as it is impossible and likely undesirable to code for "everything that is in your data," (Rubin & Rubin, 2005, p. 209), limited "criteria for interpreting findings" were applied (Yin, 1994, p. 27), with labels (or codes) identifying sub-categories created only for themes occurring in two or more transcripts. Finally, a Microsoft Excel document was then created, including the categories, the relevant data units, as well as the emergent sub-categories and their frequencies, providing a convenient visual aid to both "summarize the content of each file" (Rubin & Rubin, 2005, p. 224), as well as to facilitate the "weighing and combining" of each participant's version of the same "concept or theme," to create "a single descriptive narrative" of their meaning (p. 227).

Major Findings

Using the technology.

Often in the early stages of each interview, participants described how they currently make use of the Internet and related information technology, or have done so in the past. Upon comparing the interview data, four themes emerged, the most common being searching for information on-line (6), followed closely by email communication (5), and product or service design and development (5), and also including teaching others to use this technology (2). Searching for information and using email were especially important uses for community members, who all listed these as their primary uses for this technology. Observational data appeared to confirm these uses as primary activities at the community level, although others were also noted. For adults, on-line banking and shopping were important to some users, while for students, chatting, surfing (particularly websites of pop musicians) and playing games on-line were very popular activities. Among researchers and technical service providers, however, more variation was found. Perhaps not surprisingly, all three technical service providers reported involvement in product and service design and development, while two researchers did as well. At the same time, however, one researcher and one technical service provider also reported teaching others how to use this technology as one of their most frequent activities. Thus while community members' uses were more limited to recreational and worked-related tasks, researchers and technical service providers with sufficient skills appeared to take on a dual role—that of both IT designer and teacher.

Advantages.

Interview participants also discussed advantages they perceived as being related to their use of the Internet and related information technology. Here, the most commonly cited theme was efficiency (7), followed by cultural enhancement or protection (3), and then by flexibility (2) and inspiration for further research (2). Interestingly, responses in this area showed a marked differentiation between community members and others. Efficiency, for example, for most community members (4) referred to ease in finding information; while two technical service providers, one researcher, and only one of these community members referred specifically to increased administrative efficiency. Similarly, the remaining advantages (cultural enhancement/protection, flexibility, and inspiration for further research) were all cited by researchers and technical service providers and not by community members. Observational data seemed to confirm this trend, as through informal interviews and surveys, students and staff at CJBS overwhelmingly referred to ease in finding information as the Internet's most important advantage. While websites with local cultural relevance exist and have even been integrated into the school's curriculum, none of the community members who participated in this study specifically listed cultural promotion and/or advancement as a potential advantage of using the Internet.

Disadvantages and barriers.

Interview participants also discussed disadvantages they perceived as resulting from the use of the Internet and related information technology, along with barriers they encountered when trying to use it effectively. This section produced the greatest

variation in themes as compared to any of the others, expressed both across and within a number of themes. On the whole, the most prevalent theme was lack of time (8). Two technical service providers saw their use of this technology as limited by the time required to develop products and services as well as to administer their effective use. Three researchers and three community members, in contrast, saw their use limited by the time needed to learn the skills required to use this technology efficiently. Less frequently mentioned but possibly related disadvantages were the reported impersonality of the Internet as a communication medium (3), and the difficulties people encountered in ensuring the credibility and/or validity of the information it provides (3).

The next most frequent theme expressed in this category had to do with a perceived lack of technological skills and interest in information technology at the community level (6). Interestingly, participants' opinions varied as to whether lack of skills or lack of interest in developing these skills was the more significant disadvantage. For two technical service providers and one researcher, lack of skills was mentioned with no relationship to lack of interest. For one technical service provider and two community members, however, lack of skills and lack of interest were seen as interrelated. Next, lack of access to adequate technological resources was seen as an important barrier by two community members, and by the researcher and technical service provider with experience teaching information technology skills directly at the community level. Observational data most strongly confirmed the importance of this theme at the community level, as in surveys and informal interviews, community participants frequently expressed concerns about outdated machines, slow Internet connections and a general lack of technological

resources. Finally, according to one researcher and two technical service providers, another disadvantage in trying to use the Internet and related information technology in these communities is closely related to access issues—those caused by perceived bureaucratic and political barriers to effective adoption and use of this technology. Not only was resistance to adopting new technologies reported at the administrative level within communities, but according to some of these participants, within larger government bureaucracies as well. Interestingly, although these issues seemed important, interview participants offered few suggestions for improving access or surmounting bureaucratic and political obstacles. Instead, the most common focused on making existing equipment, such as software and websites, easier to use. To this end, three common ideas were equally offered: tailoring specific products to specific users (3), keeping these products as simple to use as possible (3), and, especially for community members, providing more education and training about information technology (3).

Ethical issues.

As a crucial component of this study, interview participants were also asked to discuss any ethical issues they saw as arising from their use of the Internet and related information technology. In this category, some differentiation between community members and others, and variation with themes also existed. First, while two technical service providers expressed concerns about the potential for on-line gambling with the use of the Internet in communities, no other participants echoed this concern. Second, in the case of the most frequently mentioned issue—concern over possible threats to users' privacy and confidentiality—community members dominated (4 of 6 responses). To

some participants, concerns were greatest in relation to specific types of information, such as personal health information, which might be considered especially sensitive. For one researcher with teaching experience, however, this concern implied both a heightened awareness of personal privacy and confidentiality concerns, as well as a potential sense of personal ethical responsibility regarding the privacy and confidentiality of others. Following discussion of concerns regarding privacy and confidentiality, interview participants expressed two additional concerns equally as often. First, several participants feared that information given over the Internet has the potential to be misused (5). Second, and importantly connected to both of the issues, the final major issue identified by one technical service provider, two researchers, and two community members was a concern that, on the whole, community members may not fully understand the implications of sharing information on the Internet, or the ensuing ethical issues that might result. In addition to being expressed by these participants, this issue was the most widely supported by the observational data gathered. While this lack of understanding appeared to be widespread within the community, community members' familiarity with Internet, along with personal security concerns such as the confidentiality of passwords, varied greatly. As well, ethical problems were only raised on one student survey, and were not generally reported as important concerns for teachers in informal interviews. These data suggest that potential ethical issues, through lack of awareness or other means, may not be seen as important by at least some community members.

Finally, as with the concerns they reported, strategies for resolving ethical issues also seemed to be split between community members and other interview participants.

Researchers and technical service providers suggested a range of options, including guidelines for research conducted using the Internet (2), seeking input from a wide range of participants (3), and discussing these issues further (2). Community members, however, overwhelmingly focused on selective use—using the Internet for sharing only certain types of information, or under certain specific circumstances (4 of 5 responses). One community member and one researcher also suggested building strong relationships as a preventative measure for potential ethical difficulties.

Summary.

Some areas of discussion analyzed in this study produced marked differences between the responses of community members and others from the outset. Perhaps least surprisingly, uses of the Internet for the majority of community members versus the majority of researchers and technical service providers were very different: while community members mainly searched for information and used email for communication, many researchers and technical service providers also reported designing and developing information technology products. More importantly, however, strong differences between the community members and other participants in this study were noted with regard to ethical issues. Here, community members overwhelmingly identified potential threats to privacy and confidentiality as their primary ethical concern, while researchers and technical service providers focused more on the potential for on-line information to be misused, and what they perceived as a lack of awareness of potential ethical issues on the part of community members. Similarly, their suggestions for resolving ethical issues were also markedly different, with community members overwhelmingly suggesting

selective use of this technology (particularly not for sensitive personal information) and researchers and technical service providers equally suggesting more discussion about ethical issues, a wide range of input into such a discussion, and also the development of guidelines for the use of the Internet as a research tool in northern communities.

In contrast, in other areas of discussion, specific themes tended to predominate across discussion with participants from all three different perspectives (community members, researchers, and technical service providers). Within these themes, however, subtle yet important differences between community members and others often arose. The main advantage, for example, as seen by almost all participants was efficiency; although the *kind* of task(s) identified as being made more efficient by the Internet were generally different for community members (who focused on finding information) and researchers and technical service providers (who focused on administrative efficiency), possibly reflecting their differing uses of this technology as noted above. A similar pattern was also seen in the discussion of disadvantages and barriers (the most internally variant topic), where different aspects of the most important themes—lack of time, lack of skills and interest, and lack of access—were also emphasized by community members as compared to researchers and technical service providers. Finally, in addition to these trends, youth continued to be an important focal point in both interview and observational data. Information about (and from) youth contributed to all methodological and ethical categories, again asserting their importance as the dominant users of information technology in northern communities.

Discussion

The analysis of data from this study reveals a number of important themes regarding methodological and ethical realities surrounding the use of the Internet and related information technology in northern communities, as identified by interview participants and through participant observation. Examining these findings in closer detail and relating them to the current literature, these themes then reveal important methodological and ethical issues that may be encountered by community members, researchers, and technical service providers alike when this technology is employed specifically to conduct research and share information.

Understanding Community

Both methodologically and ethically, themes emerging from this study revealed important differences in perception regarding advantages, disadvantages, and ethical issues surrounding the use of the Internet between community members and other participants. This suggests that a thorough understanding of the community in question is essential before any on-line health research or dissemination involving that community takes place. Far from being a novel idea, the general suggestion that researchers strive to know and respect the communities they work with is now becoming a common principle. Participatory researchers, for example, have often been criticized for romanticizing the notion of "community" as a unified, homogeneous group (Chataway, 1997; David, 2002; Emmett, 2000; Lax & Galvin, 2002), with similar skills, resources, and motivations. This is partially because, in their enthusiasm to include more community members as participants, researchers sometimes overestimate the capacity of community to

effectively participate (Dickson & Green, 2001; Krimerman, 2001; Petras & Porpora, 1993), especially when working in socially and/or economically marginalized communities, where community members may already be over-taxed in terms of their time and financial resources, and may not consider research participation as feasible or even desirable (Hondagneu-Sotelo, 1993). In the case of employing IT skills and equipment to conduct research, the potential for the same overestimation appears also to be present, as current literature tends to oversimplify a number of the complexities of engaging communities in these activities.

Understanding Disparity

While several web-based researchers have rightly criticized the disparity in access to IT skills and equipment between more and less privileged populations (Binik, et al., 1999; Cotton, 2003; Im & Chee, 2001; Mustanski, 2001; Keller & Lee, 2003; Moloney, et al., 2003; Rhodes, et al., 2003; Robinson, 2001), little discussion has taken place among these researchers concerning how to overcome this disparity. In the absence of this discussion, there is an implied assumption that simply providing those considered 'less privileged' with more and better IT equipment and training would provide a solution and therefore facilitate web-based research. Findings from this study, however, problematize this assumption in a number of ways. First, according to the literature, the fundamental barrier these 'less privileged' communities face is seen as a lack of access to adequate IT equipment and skills. Although this was confirmed by data from the community level, this data also indicated that 'lack of access' could have very different meanings to different people in different communities. While some participants expressed concerns

about outdated machines and slow Internet connections (annoyances frequently noted in my student surveys, informal interviews, and observed in the classroom), Anna, a community healthcare administrator also pointed to the importance of trained professionals within the community:

> ...we don't have the tech support, to help us... if you're—a nurse who's out in the—in the community and you're by yourself and your computer goes down, that's a pretty huge link that you have lost, to the rest of the world. And so trying to get somebody up there to, um, repair or whatever needs to be done, and you only have one person for the entire region, it's a lot for that one person to be doing—the expectations are quite high...So that can be *very* frustrating.

In a more extreme example, Sharon, an Aboriginal community member, discussed her home community in which even the suggestion of accessible computers (never mind trained information technologists) was literally laughable:

> M: So, do you think that if there was an effort to get those computers to people and to have people there, like teaching people and supporting people, in how to use these things and...so that, you know, they'd have someone to turn to if they got frustrated and they—they might not give up. Would that make a difference, to people do you think?
>
> S: ...I don't know...you have to be careful where you'd be putting your computers. I think if you put it in a...say a.... a location where someone can come in there, and...

M: Like maybe like a library?

S: Well they don't have a library…what's a library? [*we both laugh*]

Clearly, as these examples demonstrate, there is not only disparity between more and less privileged communities, but *among* less privileged communities as well; an area as yet underexplored in recent literature.

Second, evidence from this study suggests that this disparity extends not only among less privileged communities, but also reaches *between* members within these small communities; a feature with important methodological and ethical considerations for web-based research. Many researchers have widely acknowledged that access to IT skills and equipment tends to be limited to those with relatively high education and income levels (Binik, et al., 1999; Cotton, 2003; Mustanski, 2001; Keller & Lee, 2003), who themselves tend most often to be young, male, and White (Im & Chee, 2001; Moloney, et al., 2003; Rhodes, et al., 2003; Robinson, 2001). At the same time, however, others have also argued that the Internet can facilitate greater access to research for marginalized populations; such as those who would otherwise be excluded from research due to geographic location (Burton & Bruening, 2003; Cook & Rule, 2001; Fleitas, 1998; Olivero & Lunt, 2004), as well as physically disabled children (Fleitas, 1998), minority students (Shields, 2003), and autistic people (Brownlow & O'Dell, 2002). What seems largely missing from this debate is an acknowledgement that these marginalized

communities themselves are not homogenous, but also are *internally* stratified along social and economic lines. Evidence from this study points to this stratification, and the important implications it produces for the adoption and use of the Internet as a potential research tool.

A preliminary finding in this study, for example, was the indication that in northern communities, the youth appeared to have the most interest in and experience with information technology, an indication supported by observational and informal interview data at the community level. In addition, as discussed in the second chapter, all of the formal interviews I was able to secure were exclusively with non-Aboriginal community members. While these findings may certainly have been due to my limited sample and reliance on snowball sampling, other evidence suggests that they may also be indicative of trends regarding Internet access and use within the community. Observational and informal interview data, for instance, suggested that Internet access was available to very few Aboriginal students (and therefore their parents) in their homes. In addition, the Dogrib Intranet, which facilitates electronic communication throughout the Dogrib Region, was largely only accessible to community members employed by or otherwise affiliated with the regional governmental structure (mainly students, teachers, and health care workers). Finally, Sharon echoed this pattern in her comments, making the distinction between most Aboriginal members of her home community whom she said, "wouldn't have a computer anyway" and certain transplanted outsiders, "like the geologists…or someone that worked there, worked with the geologists. *They* would have computers. *They* would know about computers."

Aside from the obvious methodological limitations implied by this evidence, this internally unequal distribution of IT skills and equipment also raises significant ethical issues for community members, researchers and technical service providers alike. While some community members enjoy more access to IT skills and equipment than others, they in turn may also encounter added responsibilities and, as a result, added stress. Both formal interview and observational data suggested concern regarding the potential for stress to be caused both by and for youth in their use of the Internet and related information technology. A local teacher and technical service provider in Rae-Edzo, for example, described the students' IT skills as a "curse and a blessing," (personal communication, March 7, 2005) as he was glad to be imparting the skills to them, but also felt a responsibility to teach them to use these skills in an ethical manner. As I was able to observe, this was mostly done by his rewarding of students who had earned his trust with access to more privileged information (such as certain passwords), and by his restriction of the use of other students whom he felt had acted unethically (such as those whose chat privileges were suspended after they were caught sneaking on to teachers' computers in order to chat through the Dogrib Intranet). He also expressed concern about what students might do on the Internet at home, where they would be unprotected by the firewall in place at the school, and, he felt, they would not necessarily have the same supervision. Similarly, Michael, a technical service provider, described the situation in other northern communities as follows:

> ...these kids, when they do get on, are grabbing the things that they see...you know, and they're quick to learn...so they're grabbing that stuff and making it

their own and trans—bringing it to their communities without a total understanding of where it fits within their communities.

Importantly, one researcher even re-framed this concern into a question of ethical responsibility not only to monitor and possibly restrict the on-line activities of northern youth, but also to afford them greater opportunities, asking, "what else can they do that we don't know about, or that we're not taking *advantage* of by giving them something else to work with?"

Finally, and perhaps most importantly, some data from this study also show that for some community members, learning how to use a computer may cause as much or even more stress than lacking access to those skills. Recall, for example, from the analysis, that while the majority of participants cited efficiency as the primary advantage of using the Internet, an even larger majority cited a lack of time (either to learn about or continue to develop information technology) as its biggest disadvantage. Sharon, in her continued explanation as to why she thought web-based research would be a poor fit for her community, offers some clues to understanding this apparent contradiction:

> Computers intimidate people…so, you know, they may not go near it, for fear that, you know—I don't know if they think that they're gonna delete all of the information in there [*laughs*], but—a lot of people won't, they just—they feel—intimidated…

In her opinion, this potential intimidation would then be increased for those whose first language was not English:

> If you, if you speak in um, in broken English…I mean because your —your first language is Aboriginal…you're not gonna go and put yourself…in a position where you're going to put—put so much stress on yourself trying to answer in English…And, so…if you speak, broken English, you're not gonna go on a computer and—and…try and struggle with the, with spelling, on top of that—and learning the computer on top of that, it's just too much trouble…you know?

In fact, due to these and other concerns, such as limited literacy among some students, for the local teacher and technical service provider, the single most pressing ethical issue from his perspective was the potential for community members to be intimidated or humiliated by trying to use information technology. Perhaps this is why he and other participants stressed the importance of not only continuing to provide greater access to IT training and equipment, but ensuring that these resources are supplied in an appropriate manner (ie. keeping applications simple and tailoring them to users). Therefore, while disparity in access to IT skills and equipment presents an important ethical issue, avenues to addressing this disparity, such as providing more training and equipment, may imply significant ethical issues of their own. Or, as more simply and powerfully stated by one researcher, "If we can't make clean websites, that are easily accessible and easy to use, we're nowhere near what our full capacity is—so we're *not* 'capacity-building'—not yet."

Understanding Priorities

A final assumption that also seems to be implied in the current literature is that most members of these communities actually *want* increased access to IT skills and equipment. Evidence from this study certainly suggests that this is the case in some northern communities. Deline, for example, a mainly Sahtu Dene community located on the southern shore of Great Bear Lake, has produced two local websites, showcasing cultural, economic and political aspects of their community life. Listed among the businesses on www.deline.ca is Tech?q, Ltd., which "supports high speed Internet, and provides information technology for the community." On the same website, a prominently featured 'Deline Facts' box proudly reports, "Deline may be far away from the highway, but we have high speed Internet access." According to Anne, a researcher, at the time of this study, members of this community were in the process of developing a third website, one seen as an important opportunity for cultural preservation:

> There's lots on the Internet about what happens on special events or special occasions, but not how it's lived daily. And that's something that the community itself, in the last couple of years has become aware of, and they're actually concerned about losing what they call their 'cultural capacity.' They're actually concerned about losing—a term they came up with—they're concerned about losing, within the community, the ability, or the knowledge of how to integrate their cultural values and practices into modern life and into the future. So this funding was seen as a fantastic opportunity for them to consolidate that thinking and really take a look at, 'Well what is it that we are doing? How are we doing it now?'

This evidence seems to support the claim made by other researchers that Internet use can help to foster capacity-building and empowerment within communities (Bier, Sherblom, & Gallo, 1996; Forte, 2004; Hampton, 2003; Mehra, Bishop, Bazzell, & Smith, 2002), as here the Internet seems to be viewed as a powerful tool for cultural enhancement and protection, and a local business has emerged to support its use and ongoing development. Unfortunately, the voices of those who, for various reasons, do not feel empowered by or even interested in this technology are less frequently acknowledged and understood.

Other data from this study, however, suggest that not all communities, and not all members within a given community, will necessarily share this enthusiasm. Observational data from CJBS, for example, did not seem to indicate a strongly perceived connection between the Internet and the Dogrib culture in Rae-Edzo, despite two locally relevant websites, both of which have been integrated into the school's curriculum. Although no conclusion can be made as to why, evidence from other sources offers hints to understanding this difference, and points to instances where misunderstanding might occur from the perspective of outsiders. As an example of "a lack of understanding of IT and what IT can do" on behalf of some community members, Michael relayed the frustration of one of his colleagues, who was told by a school principal in one community that "they didn't need courses in IT because, it just, you know, it wasn't necessary in the community."

Other data suggest, however, that while this lack of understanding may exist for some people, there are other important factors that are included in decisions regarding the adoption and use of IT skills and equipment that may not be outwardly obvious. According to Sharon, for example, they may simply have other interests: "I mean hunting, fishing, boating…that—that's what's important to them, not uh, not, having a computer at home. …I just don't see that as being a…priority." In addition, competing economic priorities, at both the personal and political levels, may also effect decisions regarding access to and use of information technology. Sharon also made the following statement, posing a pointed and important question:

> It's not a priority. I mean the cost of living, is so high up there… If you have ten dollars, you know, or a hundred dollars, two hundred dollars—are you gonna spend it on a computer or are you gonna spend it to buy you groceries?

Similarly, a local technical service provider from Rae-Edzo felt that his ability to provide necessary equipment was sometimes hindered by what he saw as a political decision within the community administration not to give too much money to one institution. Although he reportedly found this limitation frustrating at times, he did not necessarily disagree with their decisions to support other community initiatives, citing the variety of challenging social issues encountered by the community's administration on a daily basis.

Finally, there is also evidence to suggest that these differing political priorities extend beyond the community level into larger government structures, where they can translate into bureaucratic nightmares for technical service providers at the community level. For

example, in response to long waits for appropriate paperwork to be completed and approved, the same local technical service provider from Rae-Edzo reported using his own money to purchase needed equipment, opting to "do it, and beg for forgiveness [and to be reimbursed] later" (personal communication, February 23, 2005). At a higher level, Michael, whose organization is dedicated to facilitating Internet access to communities across the Northwest Territories, describes a similar bureaucratic barrier related to a federal government program intended to provide Internet access for schools:

> One of the problems with Schoolnet is that it is only applicable to reserve schools…There's only one reserve school in all of the Northwest Territories. All the rest of them are run uh—are government, you know, Territorial schools even though they are in the communities where, you know, you've got a minimum probably of 80% uh—in most communities—80%…First Nations or Aboriginal students. And they are still government schools.

Thus when community members appear to lack interest in adopting and developing IT skills and equipment, a number of factors may actually be coming into play. First, as Sharon pointed out, some may actually not be very interested in the technology itself. Second, they may have other priorities, which are seen as economically and politically more important than investing in this technology. And third, they may also be discouraged from accessing programs that might relieve financial pressure and allow greater access to IT skills and equipment, simply because the process is too bureaucratically complicated and slow.

Roles and Responsibilities

As the first part of this discussion has indicated, attempting to employ the Internet as a data collection and dissemination tool in northern communities requires a detailed and sophisticated understanding of 'community' on the part of researchers and technical service providers. At the same time, however, data from this study also indicate that communities, researchers, and perhaps technical service providers themselves could also benefit from a more open and detailed discussion of the roles and responsibilities they may be expected to fulfill as keepers of highly specialized technical knowledge and expertise. As discussed in the first chapter, while web-based researchers have frequently mentioned the need to employ trained IT specialists in the design and implementation of their research tools, this literature has not provided a detailed discussion of the ethical challenges and obligations these professionals may face. Evidence from this study highlights some of these issues, as well as suggestions for their resolution, made by these professionals themselves.

First, at the community level, those relied upon to provide information technology services may not, in fact, be trained professionals at all. Instead, they may be community members or researchers called upon to develop technological skills as a matter of necessity. For these people, whose IT skills and knowledge may be (or perceived to be) relatively higher than the community at large, added stress can be a daily reality, as they find themselves coping with day-to-day responsibilities they had not anticipated. The community-based technical service provider I observed, for example, saw himself primarily as an educator with an interest in teaching information technology skills. He

had no official certification in the IT field, and reported learning systems, software, and hardware management initially out of frustration rather than interest—he simply grew tired of waiting for problems to be fixed, so he learned how to fix them himself. Over time, people eventually came to rely on his services. Similarly, my own participation as an observer/helper in the computer lab and the library brought additional responsibilities I had not initially anticipated. In the library, for example, I designed a simple Excel spreadsheet to catalogue their stock of VHS and DVD videos, into which I entered data such as titles, subject matter and serial numbers whenever I had the time. As the weeks passed, I also continued to spend time in the computer lab, observing and occasionally participating in lessons. Through these activities, coupled with an email I sent to students and staff introducing myself and attempting to explain my research, some people clearly began to assume I had a certain level of computing skills, and would therefore be able to teach them as well. In both the library and the computer lab, some students and staff members began to approach me with problems they had using word processing software, printing, and sending emails. Eventually, one member of the maintenance staff even approached me for lessons on how to use a computer, for which we met in the lab on two separate evenings. All of this caused my role to begin to evolve rather quickly—from learner to teacher as well.

For me, this evolution was a positive experience. As a visitor largely free from other responsibilities, I was happy to help in any way that I could, and thoroughly enjoyed the chance to interact more closely with community members. At the same time, however, I could not help wondering how this experience might have been different for a permanent

community member—someone already bound to the myriad of local social and economic responsibilities. For Anna, a local health care administrator, this added responsibility was "frustrating." Although self-described as "not technologically adept," Anna reported sometimes having to "field questions from [her] staff" when they encountered problems with their computers or Internet connections. As both an expression of her need and a suggestion for a solution, she stated,

> ...it would be nice to be able to ask that, um...to just be able to say like, I'm feeling weak about say an Excel program, so I can usually access an education course, somehow...and it would be nice to be able to have people to go in to train staff in the community.

Thus for those community members who are interested (or merely motivated by necessity), acquiring increased technological skills may prove to be a burden as much as an advantage. When contemplating the use of the Internet as a tool for researching and communicating information about community health, researchers may therefore want to pause and take the time to carefully evaluate how the use of this technology itself may promote or detract from community members' overall well-being.

Second, these data also indicate that technical service providers, be they professionally trained or not, are often placed in a position of trusted authority in their management of information technology. Importantly, this concentration of power has important implications for both its holders and the wider community at large. For those put in such

circumstances, this added responsibility can often be an uncomfortable burden, as illustrated by Anne, a researcher assisting a community to develop a website:

> They asked me to write the proposal, I had to answer all the questions…We had two weeks to put this thing together and get it out. So we had limited community participation in terms of how we put the proposal together, the proposal assumptions—all of it. Which is something that, to this day, makes me a little bit uncomfortable.

In some situations, this discomfort can be compounded by the fact that there is currently virtually no enforceable regulation of Internet content. This means that technical service providers must often use their own judgment in their day-to-day facilitation of on-line activities, sometimes placing them in difficult ethical situations, such as Andrew describes below:

> …it was an open-posted forum, and some of the kids were saying things that it was up to XXX or I to decide whether it was appropriate to be on the web. So it was an open forum, but somebody's sitting in a chair in Inuvik making decisions about whether to permit somebody to publish an opinion—that's a bit of an ethical dilemma. I mean it's—it was and it wasn't, because a lot of them were just—it was profanity or it was very negative…But at the same time, you're not really permitting a free flow of ideas if you're going to impose censure of any kind. But in the same conversation you have to ensure a certain level of decorum and, especially when you're dealing with children, you have to be careful of what you're facilitating to be, sort of, read and interpreted.

Perhaps most alarmingly, those placed in the role of providing and managing information technology services, trained professionals or not, may also find themselves having to police their own activities. One researcher gave a telling account of her own struggle to resist using her advanced technical skills to violate another user's privacy:

> ...recently, at home, [I was] doing work for [a relative], trying to clean up her C-drive, and I could see what my young [relative] had been doing because I know how to get into the background, and so it was a challenge for me to decide that I shouldn't be looking at either her emails or where she was going. I mean I had to make that decision, to protect her privacy, and it was very hard, because she has a—it's a very bad situation for her—she's having a lot of problems but, it's also important to realize that she needs to tell me what they are, rather than me trying to be subversive. So, it's a challenge.

These examples are not meant to imply that technical service providers will necessarily engage in any unethical behaviour. Instead, they are intended to demonstrate the added responsibilities these individuals face, and also to raise an important additional point: not only might additional stress be caused for those deemed responsible for managing this technology, but in cases like these, *all* members of the wider community are being left out of the discussion about how this technology should be used most appropriately. In the current academic climate, where more inclusive and participatory research strategies are recommended, such exclusion itself can be seen as a major ethical issue in need resolution. It is perhaps not surprising, then, that the suggestions for resolving ethical

issues made most often by researchers and technical service providers are for increased discussion of potential ethical issues with a wide range of participants, possibly leading to the formulation of guidelines.

Conclusions

As discussed in the first two chapters, this study represents an attempt to include and examine perspectives from different microsystems—those of communities, technical service providers, and researchers—within the developing research mesosystem of Network North. Through comparing and analyzing these perspectives, this study attempted to provide a preliminary basis for answering the larger question, *what are the salient ethical and methodological issues regarding the use of the Internet as a health research and dissemination tool in northern Aboriginal communities*? Analyzing the data collected through literature reviews, interviews, and participant observation revealed both common and divergent viewpoints regarding potential methodological ethical issues, particularly as envisioned by community members as opposed to technical service providers and researchers.

Examining these findings in closer detail, three major indications for both members of Network North, as well as other community members, technical service providers, and researchers contemplating similar projects become apparent. First, the discussion of the external and internal diversity and complexity of information technology in northern Aboriginal communities reveals that a thorough understanding of these microsystems and their unique dynamics is necessary for the feasible and ethical use of the Internet as a tool

for researching with them. The data from this study suggest that this understanding might be enhanced for all parties involved through investigating a number of issues in greater detail, including: (a) what kind of computing equipment is available at the community level; (b) who has regular access to this equipment; (c) what capacity for using this equipment currently exists; (d) what level of awareness of the potential ethical implications of this use exist within the community; and, perhaps most importantly, (e) if increased access to equipment, skills, and ethical awareness is necessary, does the community feel that addressing these issues is a significant priority when compared with other economic, social, and cultural needs? A future study, perhaps in the form of a comprehensive, community-based ethnography might be especially useful for more thoroughly addressing these issues.

Second, the discussion of the roles and responsibilities of technical service providers (or those acting as such) brings to light a taste of the unique practical and ethical challenges they may face in their position as both facilitators and gatekeepers of powerful, specialized knowledge. Again, data from this study suggest that a greater understanding of these challenges and their implications may be gained through further investigation of specific issues at the community level, including: (a) who is being relied upon to provide information technology; (b) what kinds of support (educational, financial, and human) are available to these providers; (c) what kinds of ethical decisions they are being called upon to make; and finally (d) (how) should the wider community be involved in those decision-making processes? In addition to an ethnography as suggested above, an additional, perhaps phenomenological study, focusing specifically on the experiences of

technical service providers may not only also be useful, but valuable to these providers themselves, as several in this study indicated a desire to discuss these issues further.

Third and finally, any further investigation into any of these issues must also acknowledge the ethical difficulties inherent in any such investigation. Recall from the discussion of the ethical concerns encountered during this study in the second chapter, for example, the need to pay special attention to the social and political contexts in northern Aboriginal communities; a need I chose to address through a limited participatory research design, and by exercising my own judgment regarding appropriate levels of interview and observational contact with community members. Importantly, this need for reliance on personal judgment was even greater when this contact took place through the Internet—for which no enforceable guidelines for ethical research behaviour are currently established. In both of those instances, richer data and therefore the potential for stronger and more trustworthy conclusions were omitted in favour what I perceived to be the most ethical conduct in my particular research context. While it is important to note that this is a single study conducted by a relatively inexperienced graduate researcher, these ethical dilemmas may still serve as important reminders for future researchers—both of the need to investigate these issues further (so that perhaps, such guidelines can be developed), as well as the need to do so extremely carefully, as studies of this kind are largely unprecedented. Given these limitations, it may be wisest for participatory qualitative researchers to use the Internet as a supplementary (Robinson, 2001) rather than primary vehicle for conducting research.

REFERENCES

Alaska Native Knowledge Network. (2001). Code of conduct for research in Indigenous communities (draft). *Sharing Our Pathways, 6*(1).

American Academy of Pediatrics. (2004). Ethical considerations in research with socially identifiable populations. *Pediatrics, 113*(1), pp. 148-151.

Archibald, J. (1993). Researching with mutual respect. *Canadian Journal of Native Education, 20*(2), pp. 189-192.

Argyris, C., & Schön. (1991). Participatory action research and action science compared: A commentary. In W.F. Whyte (Ed.), *Participatory action research* (pp. 85-96). Newbury Park, CA: Sage Publications.

Assembly of Alaska Native Educators. (2000). *Guidelines for respecting cultural knowledge*. Accessed June 25, 2004 from www.ankn.uaf.edu/standards/cultural.doc.html

Association of Canadian Universities for Northern Studies. (1998). *Ethical principles for the conduct of research in the north*. Ottawa, ON: Association of Canadian Universities for Northern Studies.

Aurora Research Institute. (2004). *Doing research in the Northwest Territories: A guide for researchers (Revised ed.).* Inuvik, NT: Aurora Research Institute.

Barry, D.T. (2001). Assessing culture via the Internet: Methods and techniques for psychological research. *CyberPsychology & Behavior, 4*(1), pp. 17-21.

Bellini, C.G.P, & Vargas, L.M. (2003). Rationale for Internet-mediated communities. *CyberPsychology & Behavior, 6*(1), pp. 3-14.

Bernard, H.R. (2000). *Social research methods: qualitative and quantitative approaches.* Thousand Oaks, CA: Sage Publications.

Bier, M.C., Sherblom, S.A., & Gallo, M.A. (1996). Ethical issues in a study of Internet use: Uncertainty, responsibility, and the spirit of research relationships. *Ethics & Behavior, 6*(2), pp. 141-151.

Bill C-14: The Tlicho Land Claims and Self-Government Act, Statutes of Canada, c.1. (Hurley, 2003). Accessed May 13, 2005 from http://www.parl.gc.ca/common/Bills_ls.asp?Parl=38&Ses=1&ls=C14

Binik, Y.M., Mah, K., & Kiesler, S. (1999). Ethical issues in conducting sex research on the Internet. *The Journal of Sex Research, 36*(1), pp. 82-90.

Boog, B.W.M. (2003). The emancipatory character of action research, its history and the present state of the art. *Journal of Community & Applied Social Psychology, 13*, pp. 426-438.

Bopp, J., Bopp, M., Brown, L., & Lane, P. (1985). Code of Ethics. In *The Sacred Tree (2nd edition)* (pp. 74-82). Lethbridge, AB: Four Worlds Development Press.

Bronfrenbrenner, U. (1994). Ecological models of human development. In T. Houston & T.N. Postlethwaite (Eds.), *International encycolopedia of education (2nd ed.)*, Volume 3. New York: Elsevier Science, pp. 1643-1647.

Brown, M. (In press). *Research, respect and responsibility: A critical review of the Tri-Council Policy Statement: Ethical conduct for research involving humans in Aboriginal community-based research.* Edmonton, AB: Canadian Circumpolar Institute Press. Accepted for publication June, 2005.

Brownlow, C., & O'Dell, L. (2002). Ethical issues for qualitative research in on-line communities. *Disability & Society, 17*(6), pp. 685-694.

Bubolz, M.M., & Sontag, M.S. (1993). Human Ecology Theory. In P.G. Boss, W.J. Doherty, R. LaRossa, W.R. Schumm, & S.K. Steinmetz (Eds). *Sourcebook of family theories and methods: A contextual approach* (pp. 419-448). New York: Plenum Press.

Burton, L.J., & Bruening, J.E. (2003). Technology and method intersect in the online focus group. *QUEST, 55*, pp. 315-327.

Cameron, G., Hayes, V.E., & Wren, A.M. (2000). Using reflective process in community-based participatory action research. *Reflective Practice, 1*(2), pp. 215-230.

Cancian, F.M. (1993). Conflicts between activist research and academic success: Participatory research and alternative strategies. *The American Sociologist, Spring*, pp. 92-106.

Chataway, C.J. (1997). An examination of the constraints on mutual inquiry in a participatory action research project. *Journal of Social Issues, 53*(4), pp. 747-765.

Chief Jimmy Bruneau School. (2004). *School Review: Chief Jimmy Bruneau School.* Rae-Edzo, NT: Chief Jimmy Bruneau School.

Childress, C.A., & Asamen, J.K. (1998). The emerging relationship of psychology and the Internet: Proposed guidelines for conducting Internet intervention research. *Ethics & Behavior, 8*(1), pp. 19-35.

Community Information and Epidemiological Technologies Canada. (2003). *Key documents on ethics in Aboriginal health research: Overview prepared for the Colloquim on ethics on Aboriginal health research hosted by the Anisnawbe Kekendazone Centre (Ottawa ACADRE) Network, 5-6 November, 2003, Ottawa, Canada*. Ottawa, ON: CIET Canada.

Cooke, R., & Rule, S. (2001). When face to face won't work: Internet-based focus groups. In *Growing Partnerships for Rural Special Education*, San Diego, CA: March 29-31. (ERIC Document Reproduction Services No. ED453039)

Cotton, A.H. (2003). The discursive field of web-based health research: Implications for nursing research in cyberspace. *Advances in Nursing Science, 26*(4), pp. 307-319.

Council of Yukon First Nations. (2000). *Traditional knowledge research guidelines: A guide for researchers in the Yukon*. Whitehorse, YT: Council of Yukon First Nations.

Creswell, J.W. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks, CA: Sage Publications.

Daniels, D. (2004). Canada's northern indigenous perspectives on distance learning. In L. Pekkala, W. Greller, A. Krylov, L. Kullerud, S. Myrdal, O. Shellman, et al. (Eds.), *On top of it: Overcoming the challenges of ICT and distance education in*

the Arctic (pp. 57-61). Rovaniemi, Finland: University of the Arctic Press and University of Lapland Faculty of Education

David, M. (2002). Problems of participation: The limits of action research. *Social Research Methodology, 5*(1), pp. 11-17.

DeLorme, D.E., Zinkham, G.M., & French, W. (2001). Ethics and the Internet: Issues associated with qualitative research. *Journal of Business Ethics, 33*, pp. 271-286.

Dene Cultural Insitute. (1993). *A participatory process for Dene/Métis communities: Exploring community-based research concerns for Aboriginal Communities*. Hay River Dene Reserve, NT: Dene Cultural Institute.

Dey, I. (1993). *Qualitative data analysis: A user-friendly guide for social scientists*. New York, NY: Routledge.

Dickson, G., & Green, K.L. (2001). Participatory action research: Lessons learned with Aboriginal grandmothers. *Health Care for Women International, 22*, pp. 471-482.

Eaton, J., & Struthers, C.W. (2002). Using the Internet for organizational research: A study of cynicism in the workplace. *CyberPsychology & Behavior, 5*(4), pp. 305-313.

Eichhorn, K. (2001). Sites unseen: Ethnographic research in a textual community. *Qualitative Studies in Education, 14*(4), pp. 565-578.

Ess, C. & Jones, S. (2004). Ethical decision-making and Internet research: Recommendations from the AoIR Ethics Working Community. In E.A. Buchanan (Ed.), *Readings in virtual research ethics: Issues and controversies* (pp. 27-36). Hershey, PA: Information Science Publishing.

Eysenbach, G., & Till, J.E. (2001). Ethical issues in qualitative research on Internet communities. *BMJ, 323*, pp. 1103-1105.

Fleitas, J. (1998). Spinning tales from the World Wide Web: Qualitative research in an electronic environment. *Qualitative Health Research, 8*(2), pp. 283-292.

Flicker, S., Haans, D., & Skinner, H. (2004). Ethical dilemmas in research on Internet communities. *Qualitative Health Research, 14*(1), pp. 124-134.

Forte, M. (2004). Co-construction and field creation: Website development as both an instrument and relationship in action research. In Buchanan, E.A. (Ed.), *Readings in virtual research ethics: Issues and controversies*. Hershey, PA: Information Science Publishing.

Freire, P. (1993). *Pedagogy of the oppressed* (M. Bergman Ramos, Trans.) New York: Continuum Press.

Gibson, N. & Gibson, G. (1999). Articulating the agendas: Negotiating a collaborative model for public health research. In D.Wall, M.M.R. Freeman, P.A. McCormack, M. Payne, E.E. Wein, & R.W. Wein. (Eds). *Securing northern futures: Developing Research Partnerships* (pp. 109-114). Edmonton, AB: CCI Press.

Gibbon, M. (2002). Doing a doctorate using a participatory action research framework in the context of community health. *Qualitative Health Research, 12*(4), pp. 546-558.

Goulet, J.A. (1998). *Ways of knowing: Experience, knowledge and power among the Dene Tha*. Lincoln, Nebraska: University of Nebraska Press.

Government of the Northwest Territories, Bureau of Statistics (2004a). *By the Numbers.* Accessed May 13, 2005 from www.stats.gov.nt.ca

Government of the Northwest Territories, Bureau of Statisics (2004b). *Rae-Edzo – Statistical Profile.* Accessed May 13, 2005 from www.stats.gov.nt.ca

Haig-Brown, C., & Archibald, J. (1996). Transforming First Nations research with respect and power. *Qualitative Studies in Education, 9*(3), pp. 245-267.

Hampton, K.N. (2003). Grieving for a lost network: Collective action in a wired suburb. *The Information Society, 19*, pp. 417-428.

Hondagneu-Sotelo, P. (1993). Why advocacy research? Reflections on research and activism with immigrant women. *The American Sociologist, Spring*, pp. 56-68.

Im, E.O., & Chee, W. (2001). A feminist critique on the use of the Internet in nursing research. *Advances in Nursing Science, 23*(4), pp. 67-82.

Im, E.O., & Chee, W. (2004). Issues in an Internet survey among midlife Asian women. *Health Care for Women International, 25*, pp. 150-164.

International Society of Ethnobiology. (1998). Code of Ethics. Accessed June 25, 2004 from http://guallart.anthro.uga.edu/ISE/soceth.html.

Inuit Tapirisat of Canada. (1993). *Negotiating research relationships in the north*. Ottawa, ON: Inuit Tapirisat of Canada.

Kahnawake Schools Diabetes Prevention Project. (1997). *Code of research ethics*. Kahnawake, QC: Kateri Memorial Hospital Center.

Kaufert, J., Commanda, L., Elias, B., Grey, R., Kue Young, T., & Masuzumi. (1999). Evolving participation of Aboriginal communities in health research ethics review: The impact of the Inuvik workshop. *International Journal of Circumpolar Health, Conference Report 58*, pp. 134-144.

Keen, J. & Packwood, T. (1996). Case study evaluation. In May, N. & Pope, C. (Eds.). *Qualitative research in Health Care*. London, UK: BMJ Publishing Group, pp. 59-67.

Keller, H.E., & Lee, S. (2003). Ethical issues surrounding human participants research using the Internet. *Ethics & Behavior, 13*(3), pp. 211-219.

Korsmo, F.L. & Graham, A. (2002). Research in the North American North: Action and reaction. *Arctic, 55*(4), pp. 319-328.

Kowalsky, L.O., Verhoef, M.J., Thurston, W.E., & Rutherford, G.E. (1996). Guidelines for entry into an Aboriginal community. *Canadian Journal of Native Studies, 26*(2), pp. 267-282.

Kuhmunen, H.M. (2003). Samenet – The Sámi information and communication network. *Indigenous Affairs, 2*, pp. 39-44.

Lakeman, R. (1997). Using the Internet for data collection in nursing. *Computers in Nursing, 15*(5), pp. 269-275.

Lawson, D. (2004). Blurring the boundaries: Ethical considerations for online research using synchronous CMC forums. In E.A. Buchanan (Ed.), *Readings in virtual research ethics: Issues and controversies* (pp. 80-99). Hershey, PA: Information Science Publishing.

Lax, W., & Galvin, K. (2002). Reflections in a community action research project: Interprofessional issues and methodological problems. *Journal of Clinical Nursing, 11*, pp. 376-386.

Lincoln, Y.S. (1998). Commodification and contradiction in academic research. *Studies in Cultures, Organizations, & Societies, 4*, pp. 263-278.

Lindsey, E., & McGuinness, L. (1998). Significant elements of community involvement in participatory action research: Evidence from a community project. *Journal of Advanced Nursing, 28*(5), pp. 1106-1114.

Macaulay, A.C. (1994). Ethics of research in Native communities. *Canadian Family Physician, 40*, pp. 1888-1890.

Mackenzie Gas Project. (2005). *Project phases*. Accessed May 13, 2005 from . http://www.mackenziegasproject.com

Maczewski, M., Storey, M.A., & Hoskins, M. (2004). Conducting ethical qualitative research in Internet-mediated research environments. In E.A. Buchanan (Ed.), *Readings in virtual research ethics: Issues and controversies* (pp. 62-78). Hershey, PA: Information Science Publishing.

Marshall, C., & Rossman, G.B. (1999). *Designing qualitative research (3rd ed.)*. Thousand Oaks, CA: Sage Publications.

Mason, J. (1996). *Qualitative researching*. New York: Sage Publications.

McCormick, R.M. (1998). Ethical considerations in First Nations counseling and research. *Canadian Journal of Counselling, 32*(4), pp. 284-297.

McTaggart, R. (1998). Is validity really and issue for participatory action research? *Studies in Cultures, Organizations, and Societies*, 4, pp. 211-236.

Mehra, B., Bishop, A.P., Bazzell, I., & Smith, C. (2002). Scenarios in the Afya project as a participatory action research (PAR) tool for studying information seeking and use across the "digital divide." *Journal of the American Society for Information Science and Technology, 53*(14), pp. 1259-1266.

Menzies, C.R. (2001). Reflections on research with, for, and among Indigenous Peoples. *Canadian Journal of Native Education, 25*(1), pp. 19-35.

Mi'kmaq College Institute. (2000). *Mi'kmaq Ethics Watch*. Antigonish, NS: Mi'kmaq College Institute.

Moloney, M.F., Dietrich, A.S., Stickland, O., & Myerburg, S. (2003). Using Internet discussion boards as virtual focus groups. *Advances in Nursing Science, 26*(4), pp. 274-286.

National Aboriginal Health Organization. (2002). *Governance of research involving human subjects: Research brief*. Ottawa, ON: Organization for the Advancement of Aboriginal Peoples' Health.

North American Primary Care Research Group. (1998). *Responsible research with communities: Participatory research in primary care. NAPCRG Policy Statement*. Leawood, KS: North American Primary Care Research Group.

Nosek, B.A., Banaji, M.R., & Greenwald, A.G. (2002). E-research: Ethics, security, design and control in psychological research on the Internet. *Journal of Social Issues, 55*(1), pp. 161-176.

Nunavut Research Institute. (2004). *Scientific research licensing in Nunavut: Guidelines and appendices*. Iqaluit, NT: Nunavut Research Institute.

Olivero, N., & Lunt, P. (2004). When ethic is functional to the method: The case of e-mail qualitative interviews. In E.A. Buchanan (Ed.), *Readings in virtual research ethics: Issues and controversies* (pp. 101-113). Hershey, PA: Information Science Publishing.

O'Neil, J.D., Kaufert, J.M., Kaufert, P.L., & Koolage, W.W. (1993). Political considerations in health-related participatory research in Northern Canada. In N. Dyck & J.B. Waldram (Eds.). *Anthropology, public science, and Native peoples in Canada* (pp. 215-232). Montreal, QC: McGill-Queen's University Press.

Pain, R., & Francis, P. (2003). Reflections on participatory research. *Area*, 35(1), 46-54.

Petras, E.M., & Porpora, D.V. (1993). Participatory research: Three models and an analysis. *The American Sociologist, Spring*, pp. 107-125.

Pittinger, D.J. (2003). Internet research: An opportunity to revisit classic ethical problems in behavioral research. *Ethics & Behavior, 13*(1), pp. 45-60.

Plainspeak. (2003). *A Plainspeak summary: Tlicho land claims and self-government agreement*. Toronto, ON: Plainspeak Cultural Awareness.

Reardon, K.M. (1998). Participatory action research as service learning. *New Directions for Teaching & Learning, 73*, pp. 57-64.

Rhodes, S.D., Bowie, D.A., & Hergenrather, K.C. (2003). Collecting behavioural data using the world wide web: Considerations for researchers. *Journal of Epidemiology & Community Health, 57*, 68-73.

Roberts, G. & Dick, B. (2003). Emancipatory design choices for action research practitioners. *Journal of Community & Applied Social Psychology, 13*, pp. 486-495.

Roberts, L., Smith, L., & Pollock, C. (2004). Conducting ethical research online: Respect for individuals, identities and the ownership of words (pp. 156-173). In E.A. Buchanan (Ed.), *Readings in virtual research ethics: Issues and controversies* (pp. 156-173). Hershey, PA: Information Science Publishing.

Robinson, K.M. (2001). Unsolicited narratives from the Internet: A rich source of qualitative data. *Qualitative Health Research, 11*(5), pp. 706-714.

Rodriguez, N.B. (2003). Weaving tapestries of solidarity with virtual thread: Information and communication technologies at the service of grassroots Indigenous women in Bolivia. *Indigenous Affairs, 2*, pp. 26-31.

Rubin, H.J., & Rubin, I.S. (2005). *Qualitative interviewing: The art of hearing data (2nd ed)*. Thousand Oaks, CA: Sage Publications.

Ryan, J., & Robinson, M.P. (1990). Implementing participatory research in the Canadian North: Case study of the Gwich'in Language and Cultural Project. *Culture, 10*(2), pp. 57-71.

Salmon, G. (2002). Mirror, mirror on my screen…Exploring online reflections. British *Journal of Educational Technology, 33*(4), pp. 379-391.

Shields, C.M. (2003). 'Giving voice' to students: Using the Internet for data collection. *Qualitative Research, 3*(3), pp. 397-414.

Simonson, L.J., & Bushaw, V. (1993). Participatory action research: Easier said than done. *The American Sociologist, Spring*, pp. 27-37.

Sixsmith, J., & Murray, C.D. (2001). Ethical issues in the documentary data analysis of Internet posts and archives. *Qualitative Health Research, 11*(3), pp. 423-432.

Small, S.A. (1995). Action-oriented research: Models and methods. *Journal of Marriage & the Family, 57*, pp. 941-955.

Sontag, M.A., & Bubolz, M.M. (1998). A human ecological perspective for integration in home economics. In *Human ecology research and applications*. Second International Conference of SHE. College Park, MD: Society for Human Ecology, pp. 150-159.

Stager, J. (Ed.). (1994). *Canada and polar science: Proceeding of a conference sponsored by the Canadian Polar Commission, Yellowknife, N.W.T., May 17-19, 1994*. Ottawa, ON: Canadian Polar Commission.

Trochim, W.M.K. (2001). *The research methods knowledge base (2nd ed.)*. Cincinnati, OH: Atomic Dog Publishing.

U.S. Interagency Arctic Research Policy Committee. (1995). Principles for the conduct of research in the Arctic. *Arctic Research of the United States, 9*, pp. 56-57.

Westney, Q.E., Brabble, E.W., & Edwards, C.G. (1988). Human ecology: Concepts and perspectives. In *Human ecology research and applications*. Second International Conference of SHE. College Park, MD: Society for Human Ecology, pp. 129-137.

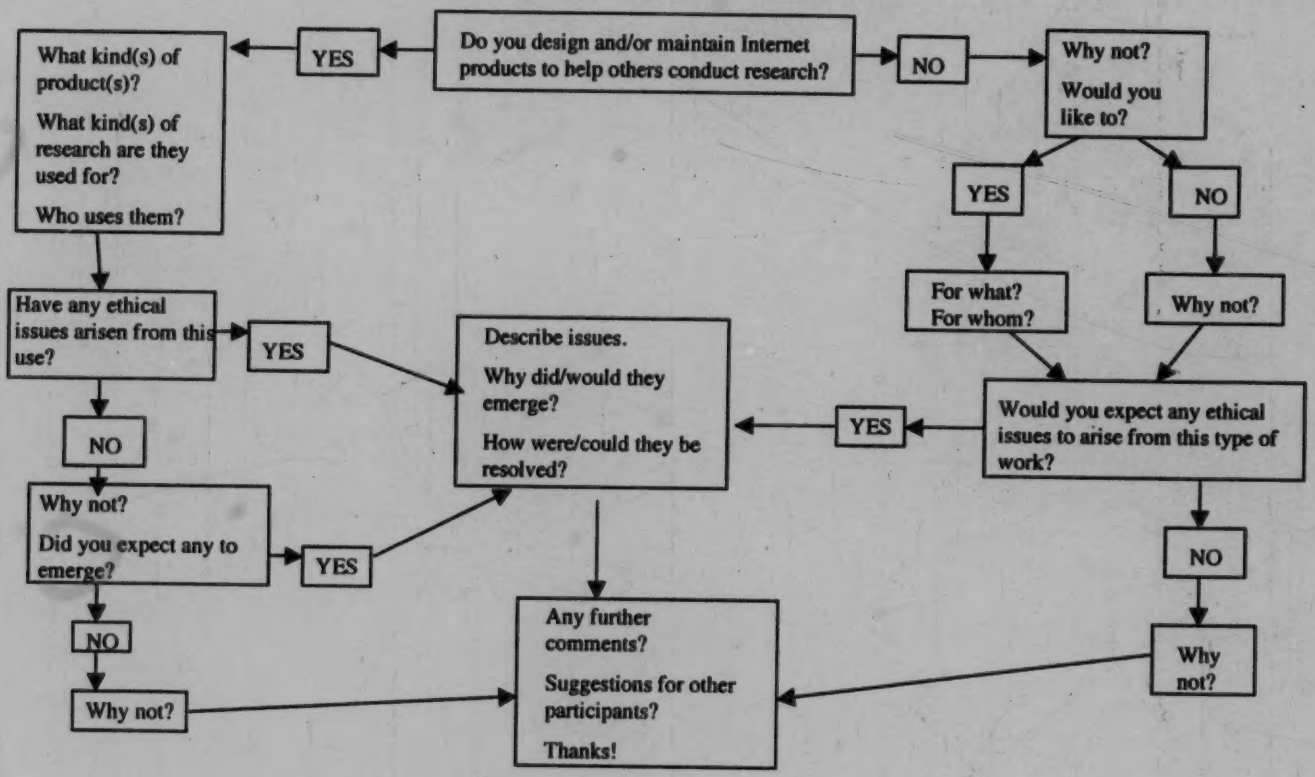
Van Maanen, J. (1983). Reclaiming qualitative methods for organizational research: A preface. In J. Van Maanen (Ed.), *Qualitative methodology* (pp. 9-13). Newbury Park, CA: Sage.

Yin, R.K. (1994). *Case study research: Design and Methods (2nd Ed.)*. Thousand Oaks, CA: Sage.

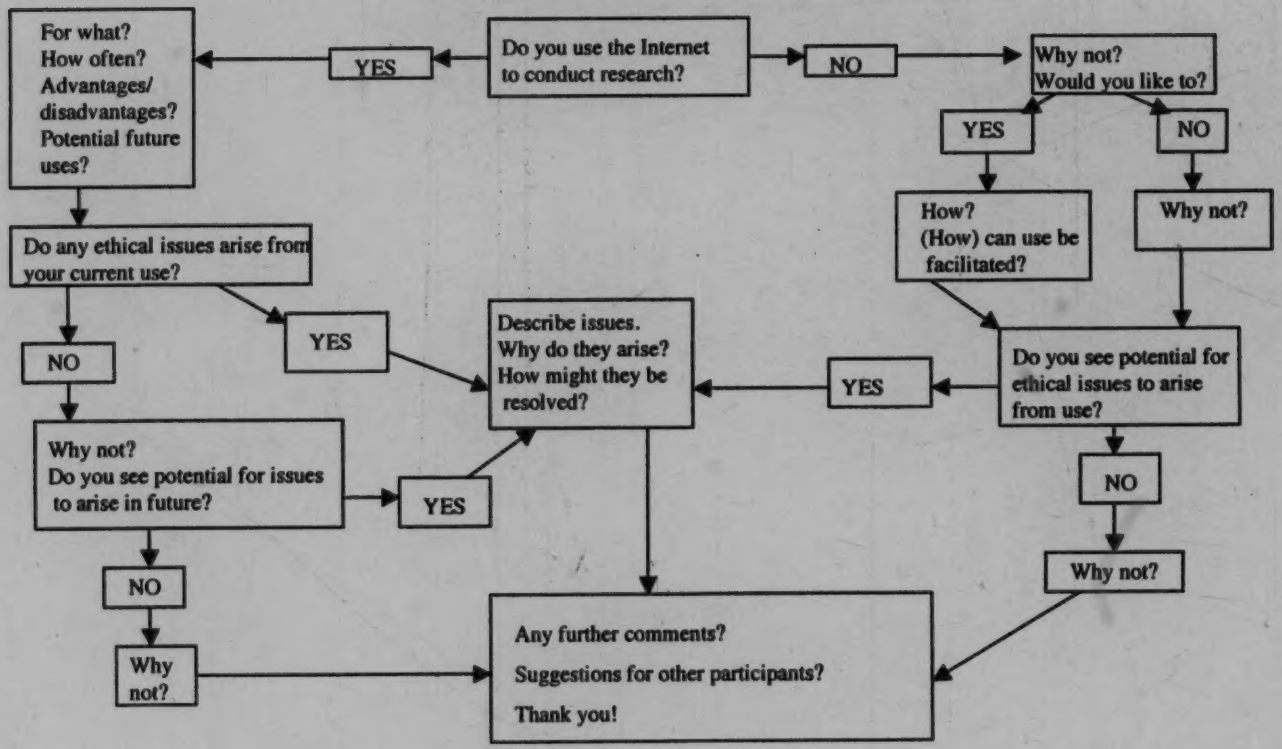
Young-Ing, G. (2003). Perspectives on the Indigenous tradition/new technology interface. *Indigenous Affairs*, 2, pp .14-17.

Yukon Heritage Branch, Department of Tourism. (2001). *Guidebook for scientific research in the Yukon*. Whitehorse, YT: Yukon Heritage Branch.

APPENDIX A: SERVICE PROVIDER INTERVIEW



APPENDIX B: COMMUNITY/RESEARCHER INTERIVEW


Do you use the Internet to conduct research?
YES
For what? How often? Advantages/ disadvantages? Potential future uses?
NO
Why not? Would you like to?
YES
NO
How? (How) can use be facilitated?
Why not?
Do any ethical issues arise from your current use?
YES
NO
Describe issues. Why do they arise? How might they be resolved?
YES
Do you see potential for ethical issues to arise from use?
Why not? Do you see potential for issues to arise in future?
YES
NO
NO
Why not?
Why not?
Any further comments?
Suggestions for other participants?
Thank you!

APPENDIX C: STUDENT SURVEY

CJBS Internet Use Survey

******Please DO NOT write your name on this paper.**

For questions 1, 2, and 3, please circle your answer.

1. Do you use the Internet at school?	Yes	No	Don't Know
2. Do you use the Internet at home?	Yes	No	Don't Know
3. Do you feel safe when you are using the Internet?	Yes	No	Don't Know

For questions 4, 5, 6, and 7, please write your answer in the space provided. If you need more space, please write on the back of the paper.

4. What do you do on the Internet?

5. What do you like about using the Internet?

6. What DON'T you like about using the Internet?

7. Would you like to write anything else? (Please write below this question).